

**CITIZENSHIP, SOCIAL WORK
AND DISABLED PEOPLE IN MALAYSIA**

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ABSTRACT

Within the wider renaissance of the citizenship debate and the social model of disability, this thesis on citizenship, social work and disabled people, attempts to establish the value and applicability of a citizenship model of social work practice among disabled people in Malaysia. The citizenship model is developed through a critical review of the relevant literature on citizenship, disability and social work in relation to Malaysian economic, social and political development. Its value and applicability are assessed through empirical research on policy, organisation and practice in services for disabled people in Malaysia.

Three aspects of social welfare are addressed and integrated throughout this thesis. Firstly, citizenship; secondly, disability theories and models; thirdly, disabled people and voluntary organisations in the Klang valley region of Malaysia.

In this study a collaborative action research method was utilized and this has facilitated disabled people's participation in the research together with an opportunity to introduce the findings directly to voluntary organisations under study. Furthermore, the attempt in this study to link macro and micro concerns, theory and practice, quantitative and qualitative approaches in one field study, has potential for further development.

Through a comprehensive overview of thirty one voluntary organisations based in the Klang valley region of Malaysia, a four-fold typology of organisations emerged namely charity care, enabling care, advocacy and self-help. Further analysis identified clear differences in priorities and programmes adopted by voluntary organisations controlled and managed by disabled people and those by non-disabled people. This analysis was further confirmed with an in-depth study of two organisations, one from each of these two categories .

This thesis reveals that disabled people in Malaysia can make a claim for their membership and inclusion in Malaysian society based on citizenship rights and responsibilities. Consistent with citizenship principles, disabled people themselves and their organisations will have to continue to take the lead not only at the level of analysis and advocacy but also in developing creative alternative services which afford disabled people ownership and control. The implications of this development for both the public and voluntary sectors controlled and managed by non-disabled people are identified.

DEDICATION

TO ROSE

*my beloved wife, friend & partner in life,
for your patience, support, understanding, & sacrifice
while I undertook this doctoral research.
But most of all for the confidence you have in me
and your determination to see me through*

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*Not to us, O Lord, not to us but to your name be the glory,
because of your love and faithfulness (Psalm 115:1)*

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GLOSSARY

Frequently used terms in this thesis. Explanation for the use in provided in the text.

Disabled people	Preferred term in contrast to people with disabilities
Non-disabled people	Preferred term in contrast to able-bodied
'Organisations for'	Voluntary organisations set up and controlled by non-disabled people
'Organisations of'	Voluntary organisations set up and controlled by disabled people
VISION 2020	Malaysian vision to be an industrial nation by the year 2020

ABBREVIATIONS

Frequently used abbreviations in this thesis.

CBR	Community Based Rehabilitation
CC	Charity care
CCO	Charity care organisation
EC	Enabling care
MCD	Malaysian Confederation of the Disabled
MCR	Malaysian Council for Rehabilitation
NSWC	National Social Welfare Council
SH	Self-help
SHO	Self-help organisation
RM	Ringgit Malaysia, which is the Malaysian dollar (value £ 1.00 = RM \$ 3.80)

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INTRODUCTION

Citizenship is at the heart of contemporary debates among political philosophers and welfare theorists (Turner 1986, 1990, 1993; Held, 1989; Young, 1989; Heater, 1990; Plant and Barry 1990; Oliver and Heater, 1994; Roche, 1992; Culpitt, 1992; Kymlicka and Norma, 1994; Mario Young, 1989). This renaissance is in the following context. Firstly, the new agenda for welfare, initiated by neo-conservatism, in cutting back public expenditure on welfare and promoting market based approaches based on active citizenship. Secondly, the collapse of communism in Eastern Europe and the consequent renewed interest in civil society and its relationship to the State. Furthermore the interest in community reflected in the dialogue between communitarian and liberal traditions in political thought has also contributes to the contemporary interest in citizenship.

Marginalised groups have extended the citizenship debate by challenging the abstract liberal tradition of rights from their experience of exclusion. One such group are disabled people who are denied their citizenship on account of their disability. They are making a claim for their inclusion and membership in society on the basis of citizenship rights. (Oliver, 1993b, 1996; Barnes, 1991; Jenny Morris, 1992; Barton, 1993; Jan Walmsley, 1991, 1994). Fundamental to their claim is a reconceptualisation of disability in terms of a social model of disability (Oliver, 1983, 1990, 1996).

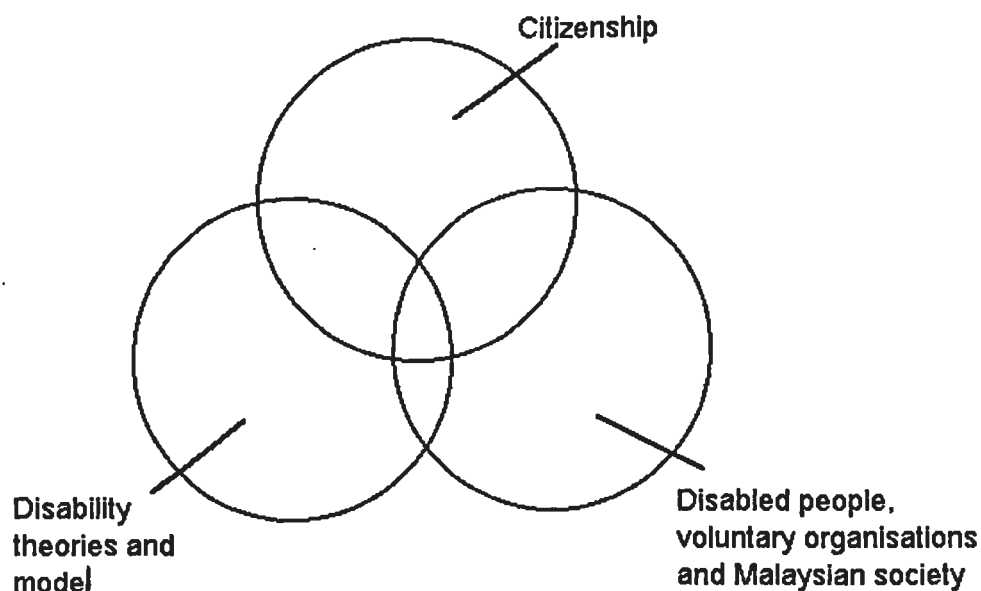
Disabled people in Malaysia are in a similar way making a claim for their inclusion on the basis of citizenship rights. (John Kim, 1990, 1995; Godfrey Ooi, 1994a, b, c, 1995; Sazli

Shaari, 1994; Esther Lim 1993, Anthony Thanasayan, 1995a, b, 1996). They argue that they should not be excluded from the economic development that Malaysia is experiencing as a newly industrialising country and now is the time to include disability concerns into national planning and implementation.

1. Research Focus

It is in this context of the wider renaissance of the citizenship debate and the social model of disability that, this study on citizenship, social work and disabled people, attempts to develop and determine the value and applicability of a citizenship model of social work practice among disabled people in Malaysia. Three aspects are crucial in this thesis. Firstly, citizenship; secondly, disability theories and models and thirdly, disabled people, and voluntary organisations in the Klang valley of Malaysia.

Figure 1 : An integrated Study



2. Central Research Question

The central research question in this thesis is,

what relevance does the current discussion on citizenship among political philosophers and welfare theorists, have for social work practice among disabled people, in Malaysia with specific reference to voluntary organisations in the Klang valley region.

Further clarity on this question is provided in Chapter Five, as sub questions are considered in the areas of Citizenship and Malaysian society, Disabled people and Malaysian society and Disabled people and voluntary organisations.

Citizenship and Malaysian Society

- (1) How is the concept of citizenship relevant to Malaysian society and readily understood by Malaysians? Is there any historical relevance and practical application to Malaysian society in general ?
- (2) Is there tension in Malaysian society between individual and collective approaches in providing equal opportunities for all Malaysians?

Disabled People and Malaysian Society

- (3) What is the position of disabled people in Malaysia, are they citizens of the nation with equal rights and responsibilities or just objects of charity ?
- (4) How do disabled people in Malaysia make a claim for their rights and what are the factors which they identify that hinder their achievement of full membership in Malaysian society?
- (5) What role have organisations run by disabled people played in challenging inappropriate approaches to practice and what action have they taken in enhancing the rights of disabled people in Malaysian society ?

Disabled People and Voluntary Organisations

- (6) What are the models and approaches which dominate social work practice in the voluntary sector in the Klang valley? How do voluntary organisations organise their services for disabled people? Is it 'with' disabled people, or 'for' disabled people?

- (7) To what extent is the citizenship model of social involvement compatible with the situation in Malaysia as a model for social work practice? What are the implications of this practice which aims to facilitate self-reliance, independence and empowerment of disabled people and their movement ?
- (8) What changes can be introduced in cooperation with disabled people to voluntary sector practice so that it provides for greater involvement of disabled people and their movements?

3. Structure of the thesis

In the ten chapters that follow, a systematic and analytical response based on an original piece of empirical research is provided. The search of primary and secondary Malaysian documents indicates that there has been no other systematic study of voluntary organisations working among disabled people in the Klang valley of Malaysia.

Chapters Two, Three and Four contain critical analyses of the literature on citizenship, disability theories and models, and Malaysian policies and provisions for disabled people. Chapter Two, provides a comprehensive review of contemporary debates on citizenship and an analysis of its relevance for disabled people in general and Malaysian society in particular. In Chapter Three, after critically reviewing different disability theories and models, the chapter concludes with an outline of a citizenship model for social work theory and practice, and for agency policy and structure. This will provided the framework for the subsequent investigation of the experiences of disabled people in Malaysia. Chapter Four, provides a macro analysis of policies and services for disabled people in Malaysia.

The methodology of enquiry into social work practice among disabled people in Malaysia with a detailed discussion on research and methodology issues, is the focus of Chapter

Five. A combination of quantitative and qualitative methods was used in an in-depth investigation of voluntary action among disabled people in the Klang valley. These were incorporated in a collaborative, participatory approach to action research with disabled people in order to determine the value and applicability of the citizenship model of social work practice in the Malaysian context.

Chapters Six, Seven, Eight and Nine provided an in depth analysis of the field study findings. A comprehensive overview of the services provided by voluntary organisations in the Klang valley is described in Chapter Six, whereas Chapter Seven, Eight and Nine explore the nature of social work practice and organisational set-up specifically in two voluntary organisations, one controlled by non-disabled people and the other by disabled people. This was done to further explore the relevance and applicability of the citizenship model of social work practice in Malaysia.

An appraisal and reformulation of the citizenship model in the light of the findings of the research completed, is the focus of Chapter Ten. An attempt is made to define policies, programmes and structures relevant for voluntary organisations working among disabled people in Malaysia from the citizenship framework.

CONTEMPORARY CITIZENSHIP DEBATES

1. Chapter Introduction

This chapter is concerned with the renaissance of the concept of citizenship among social and political theorists from the work of T.H. Marshall (1950) to contemporary times. What is being noted from the discussions are five major themes and implications namely Citizenship rights and duties; Equality; Struggle for membership; Participation; and finally Whose responsibility - State or Market. These five themes serve as the foundational framework for the enquiry into social work practice among disabled people in general and in particular disabled people in the Malaysian context.

2. RENEWED INTEREST IN CITIZENSHIP

In contemporary debates among political philosophers and welfare theorists, there is a clear renaissance of the concept of citizenship (Parker, 1975; Barbalet, 1988; Young, 1989; Turner, 1986, 1990, 1993; Heater, 1990, Roche, 1992; Culpitt, 1992; Kymlicka and Norman, 1994; Twine, 1994; Oliver and Heater, 1994). This has emerged as a result of the restructuring of the post-war welfare state in Britain. There are attempts from the left, right and centre to establish new directions in setting an agenda for the 1990s based on the notion of citizenship (Hall and Held, 1989; Plant, 1988; King, 1987; Taylor, 1992).

Roche (1992) sets the context in which this renewed interest has emerged. He identifies two sets of social forces at work, namely ideological change and social structural change. With regard to the first challenge, he notes the ideological and political challenges emerging from social movements (eg. feminism, ecology etc.), however he affirms that the greatest challenge is with the rise to power of the New Right and Neo Conservatives in

Britain and USA in the late 1970s and 1980s. The emphasis here is upon the cutback of public expenditure in welfare spending, the emphasis on voluntarism and the increased role of the family as care providers. In simplistic terms the implication is the transformation of state based welfare to a market based system associated with 'active citizenship'. The second challenge can be seen in two shifts namely, the shift from industrial to post-industrial society and the globalisation of contemporary capitalist economy.

Ian Culpitt (1992) in noting the changes taking place highlights the paradigm shift from welfare consensus to the politics of neo-conservatism. He describes the traditional welfare paradigm as one in which the State accepted direct responsibility for the welfare needs of its citizens. This saw the development of professionals who acted on behalf of the State. The new welfare paradigm according to Culpitt (1992:4) has challenged the paternalistic and professional assumptions and protects the clients from overt intervention by professionals. The impact of this paradigm shift has resulted in the retrenchment of social services and the new welfare policies aim to remove the State from direct responsibility for social service interventions. There is a successful introduction of market oriented policies as contracting out and privatisation of welfare services have emerged as self-evident in social policies. This paradigm shift has weakened the entire legitimacy of the State's role in the determination and delivery of welfare policy (Culpitt, 1992 : 8).

Social and political theorists in responding to the challenges and paradigm shift have drawn upon the work of T.H. Marshall who is recorded as 'the founder of the sociology of citizenship' (Roche, 1992 : 3). Furthermore in modern social theory, citizenship had not been a strong theme until Marshall. Roche notes that Marshall's "relatively brief discussion provided one of the earliest, clearest and most suggestive accounts of the historical and

social reasons for the emergence of the postwar 'welfare state' and of the moral and political justifications for it" (1992 : 17). His work is now regarded as a classic.

Since the 1980s British social and political theorists, for example Giddens (1981); Turner (1986, 1990, 1993); Mann (1987); Held (1989); Roche (1992) have built upon the work of Marshall by updating and establishing a critical dialogue with it, and have been instrumental in bringing about a renewal in the social analysis of citizenship.

Furthermore, the conceptual framework of citizenship has been applied to specific marginalised groups and has challenged the abstract liberal tradition of rights. It has provided the framework for neglected and marginalised groups to claim a sense of acceptance and membership as equal partners in the community. Lister (1990a) applies this framework to the poor. Smith (1989) and Ram Paul (1991) to minority racial groups and both Lister (1990b, 1995), Jones (1990), Walby (1994) and Young (1995) draw the attention to the second class status of women. The issues pertaining to disabled people are highlighted by Oliver (1990, 1993b, 1996), Barnes (1991) and Jenkin (1991). Jenny Morris (1992) makes the case that disabled women are even more neglected and Jan Walmsley (1991, 1994) addresses the complex issue of relating citizenship to people with learning difficulties.

3. MARSHALL'S DISCUSSION ON CITIZENSHIP

T.H Marshall (1950) developed this concept of citizenship based on a historical analysis of British society in its transition from a pre-industrial to an industrial society. His focus was on welfare in a generic sense. His chief concern was the development of citizenship rights and its impact on social inequality.

Marshall (1950 : 74) highlighted citizenship rights in three dimensions. First, the civil dimension is composed of the rights necessary for individual freedom - liberty of the person, freedom of speech, thought and faith, the right to own property and to conclude valid contracts, and the right to justice. Second, the political dimension is the right to participate in the exercise of political power, as a member of a body vested with political authority or as an elector of the members of such a body. Third, the social dimension which embraces

the whole range from the right to a modicum of economic welfare and security to the right to share to the full in the social heritage and to live the life of a civilised being according to the standards prevailing in the society. (Marshall, 1950 :11)

Marshall pointed out that the civil dimension is protected by the legal institution and developed mainly in the eighteenth century, and the political dimension by Parliament and developed mainly in the nineteenth century. It was only in the twentieth century that social rights were developed and catered for by the Welfare state.

Mishra (1981 : 26) acknowledges that it was Marshall who put forward the view that social services are a component of citizenship rights in a modern democratic state. Parker (1975 : 145) recognised that in so doing Marshall had set a new agenda whereby an individual citizen's living standard is safeguarded irrespective of the individual's bargaining power. In this context Turner (1986 : 108) notes the implications of what Marshall highlighted with regard to the core of social citizenship which is the right to welfare on an egalitarian basis provided by a bureaucracy which can deliver these rights.

Marshall's (1950: 57) concern was equality and therefore he exposed the paradoxical and contradictory nature of citizenship which is the notion of equality with that of capitalism

which is a system of inequality. He indicated that the two concepts, citizenship and the capitalist class system are in conflict. He argued that

the equality implicit in the concept of citizenship, even though limited in content, undermined the inequality of the class system, which was in principle a total inequality (Marshall, 1950 : 88).

Mishra (1981) in noting this discussion affirms that the paradox is more apparent than real.

He goes on to explain that for Marshall

citizenship has to do with equality of status as a member of a community and not with equality in any other sense. Thus equal status as a citizen is quite compatible with inequality in other respects, for example material rewards, resulting from the operations of the market and other structures of capitalism. (Mishra, 1981 : 28)

Marshall's contribution to social policy can be specifically noted in three areas and these have a bearing on contemporary discussions. Firstly, Marshall established that social rights are an essential part of citizenship rights. Secondly, that every citizen is to be protected and provided for by the State and that a claim can be made on the basis of entitlement. Thirdly, he revealed the contradictory nature of equality through citizenship and inequality through the capitalistic system.

Critics of Marshall have been critical of the narrow focus of Marshall's anglo-centric orientation with its reference only to Britain. Mann (1987) attacks the ethno-centricity and evolutionism of Marshall's theory. His main concern is that in Marshall's treatment there is no reference to any other country except Britain. Mann attempts to move beyond this and he develops a comparative historical analysis of industrial societies. David Held (1989 : 193) notes that while Giddens acknowledges the significance of Marshall's analysis for contemporary social and political theory, Giddens criticises Marshall for his evolutionary perspective on citizenship in which the development is unfolded in phases. Held concludes

that Marshall, according to Giddens failed to consider the wider social context within which the welfare state developed in Britain. Furthermore, that Giddens saw Marshall's account as purely a 'one way phenomenon' which is like an 'irreversible process'.

Turner (1986) acknowledges the influential role of Marshall's thoughts in sociological studies. This is especially true in the analysis of the contradictory relationship between parliamentary democracy and free market capitalism. Marshall has been more critically evaluated, says Turner, with regards to his sociology as a defence of reformism within a capitalistic society, and his historical analysis of the expansion of citizenship rights as an evolutionary view which fails to grasp its contradictory features. Marshall's notion of the hyphenated society is helpful in explaining the tensions and contradictions. The hyphenated society, according to Marshall, says Turner, is a society in which there is :

a social system in which there were perpetual tensions between the need for economic profitability, the taxation requirements of the modern state and the rights of citizens to welfare provisions (Turner, 1990 : 192).

4. EMERGING THEMES AND IMPLICATIONS

Five major themes can be identified as social and political theorists interact with Marshall, citizenship and contemporary debates. These have implications for disabled people in general and in particular for disabled people in Malaysia.

4.1 Citizenship Rights and Duties

The central accusation of the neo-conservatives is that the overemphasis on rights obscures the notion of duties. They went on to develop and promote 'active citizenship'. Oliver and Heater (1994) provide a useful summary:

The virtue of the active citizen is the altruism of voluntary social service. The impression is given that in order to become a good citizen, the individual must

surrender positive, critical political interests. The active citizen is a depoliticized voluntary worker in his or her local community. (Oliver and Heater, 1994 :130)

Roche (1992) accurately notes that the neo conservatives are guilty in their overemphasis on duties as against rights. There is a need for a balance in this issue as 'duties imply rights' and 'rights imply duties' not only in practice but also in principle. Roche (1992) goes on to advocate a progressive approach to the politics of social citizenship by calling for a rethink of the absolute priority that has been traditionally given to social rights in ideological debates. There is a need, notes Roche:

to reconsider the moral and ideological claims of personal responsibility, of parental and ecological obligations, of corporate and inter- generational obligations, and so on. The politics of citizenship has for generations formulated its goals, fought its battles and found its voice in the discourse of rights. In the late twentieth century it also needs to be able to speak, to act and to understand itself in the language of citizens' personal responsibility and social obligation in the discourse of duties as well as of rights. (Roche, 1992 : 246).

Michael Oliver (1993b) has introduced the neglected theme of disability into the discussion of citizenship rights. He clearly highlights how disabled people are denied their citizenship on account of their disability. He compares the experience of disabled people with that experienced by black people on account of their race and women on account of gender. He concludes disabled people are denied their fundamental rights as citizens in similar ways.

In the citizenship discussion on rights and duties disabled people have introduced the new theme of comprehensive legislation as a means of protecting their rights. Oliver (1993b) highlights the need for comprehensive legislation which is a necessary step to the achievement of political, social and civil rights thereby enabling disabled persons to become citizens. The legislation according to Oliver should also ensure freedom of information and the provision of proper funding.

Colin Barnes (1991) who developed a systematic analysis of institutional discrimination against disabled people in British society, advocates Anti-Discrimination Legislation. In his historical survey he concludes that while there was substantial discrimination prior to industrialisation it was relatively fragmented. It was, however, the economic and social upheavals which accompanied industrial development which precipitated discrimination becoming institutionalized throughout society. In advocating anti-discrimination legislation he acknowledges that:

policies might not remove institutional discrimination overnight but they can certainly contribute significantly to its demise (Barnes, 1991 : 234).

Furthermore Barton (1993) and Oliver (1993b) have been critical of the theory of needs and affirm the position on rights. The challenge by disabled people is to develop welfare provisions based on rights rather than needs. Examples are provided where welfare based on needs creates not only dependency but also domination by professionals. While this is an important point Ruth Lister (1993) indicates that Oliver has not provided an adequate critique of Doyal and Gough (1984, 1991). What is important to note is that disabled people are wanting their needs met on the basis of citizenship rights.

Barton (1993) critically notes that the current emphasis on citizenship by the Right centres around the theme of obligations or duties ie the 'active citizen' which reinforces dependency. This is because the emphasis on the active citizen is upon one citizen doing good for the other and in this case acting on behalf of disabled people. In contrast he says the emphasis should be upon empowerment and participatory citizenship.

4.2 Equality and Citizenship

Within the discussion of citizenship we have noted the tension between equality of status as citizens but inequality in other dimensions especially due to the capitalistic framework. The egalitarian implications of citizenship are emphasised by Julia Parker who advocates changes in social policy which should aim:

at a level of welfare reflecting normal hopes and expectations rather than at the minimum necessary for survival (Parker, 1975 : 145).

Mishra goes on further to affirm that:

the notion of citizenship is valuable in emphasising the idea of equality of status and thus indirectly questioning the legitimacy of unequalitarian social relationships or a stratified society. (Mishra, 1981 : 26)

Another dimension of the discussion on equality is raised by Marion Young (1989) who is referred to by Kymlicka and Norman (1994) as a 'cultural pluralist'. One of Young's key concerns is why has equal citizenship not eliminated oppression or rather why has the extension of equal citizenship rights not resulted in social justice and equality. Young's basic thesis is that there is a place for special rights and group representation in order to undermine oppression and disadvantage. The rationale for this as Young indicates, is that in the context where some groups are privileged and when there are differences in capacities, cultures, values and behaviour styles, the principle of equal treatment tends to perpetuate oppression or disadvantage. Furthermore, Young points out that

the privileged are usually not inclined to protect and further the interests of the oppressed partly because their social position prevents them from understanding those interests, and partly because to some degree their privilege depends on the continued oppression of others (Young 1989 : 396)

It is therefore in these circumstances that Young advocates

mechanisms for the effective representation and recognition of the distinct voices and perspectives of those of its constituent groups that are oppressed or disadvantaged within it (Young, 1989 : 395).

Group representation is seen as the most effective means to promote just outcomes.

Oppressed and disadvantaged groups need appropriate structures for group representation as well as public resources for supporting these activities. Three group activities are noted:

[1] Self-organisation of group members so that they gain a sense of collective empowerment and a reflective understanding of their collective experience and interest in the context of the society; [2] voicing a group's analysis of how social policy proposals affect them, and generating policy proposals themselves, in institutionalised contexts where decision makers are obliged to show that they have taken these perspectives into consideration; [3] having veto power regarding specific policies that affect a group directly ... (Young, 1989: 395)

Young rightly notes the dilemma of difference in the context of the universality of citizenship where there is a denial of the difference for full inclusion and participation. This is further complicated by the use of quotas and affirmative action programmes as these violate the principle of equal treatment. However Young justifies such programmes

as just compensation for groups that have suffered discrimination in the past, or as compensation for the present disadvantage these groups suffer because of that history of discrimination and exclusion (Young, 1989 : 403).

Will Kymlicka and Wayne Norman (1994) highlight the worries of the critics of differentiated citizenship, namely that this approach encourages groups to turn inward and focus on their differences rather than build a larger fraternity of all. Another worry of the critics is that differentiated citizenship creates a 'politics of grievance'. The danger noted here is that group leaders would

devote their political energy to establishing a perception of disadvantage-rather than working to overcome it-in order to secure their claim to group rights (Kymlicka and Norman, 1994 : 372).

Relating differentiated citizenship to disability does not mean segregated and isolated services for disabled people, on the contrary it is a call for universal services. Disabled people like all other citizens should be catered for in a similar way. In accordance with Young's principle, disabled people have opportunities for direct group representation in the decision making process. What is essential is more effective voice where mainstream services recognise the views and concerns of disabled people.

4.3 The struggle and meaning of membership

The early development of the theory of citizenship is now regarded by many critics as being too restrictive in its framework and application. David Held (1989) notes that both Marshall and Giddens utilised the 'class conflict framework'. While this is an important medium for the development of rights it is by no means the only way of viewing it. Held is right in acknowledging the need for an analysis which will examine the way in which different groups, classes and movements struggle to gain degrees of autonomy and control over their lives. This is because citizenship involves the struggle for membership.

The post-Marshall debate needs to extend the analysis of citizenship to take account of issues passed by, for instance, feminism, the black movement, ecology (concerned with the moral status of animals and nature) and those who have advocated the rights of children (Held, 1989 : 198)

and one might add the issues raised by the disabled people's movement. David Held further calls for a study of citizenship which transcends the terms of reference made by Marshall and Giddens. For him such a

study of citizenship has to concern itself with all those dimensions which allow or exclude the participation of people in the communities in which they live and the complex pattern of national and international relations and processes which cut across these. Neither Marshall nor Giddens has provided an adequate basis for such a study (Held, 1989 : 202 and 203).

In a similar way David Taylor, further states that

the abstract liberal tradition of rights, must come to terms with feminist and anti-racist critiques which demonstrate the failure of citizenship rights vested in liberal democratic institutions to meet the needs of women and racial groups and the socially and economically marginalised (Taylor, 1989 : 29).

There was a progressive change and more groups were included within the fold. For example one can note the extension of citizenship rights to the middle class men, then the working class men and then finally to women. It is thus imperative that the citizenship debate must now:

address not only class and inequality, but also questions of membership posed by feminism, the black and ethnic movements, ecology ... and vulnerable minorities, like children (Hall and Held, 1989 : 17) and disabled people.

Citizenship theory has the potential to be the framework by which neglected and marginalised groups can find a sense of acceptance, of being part of the community as equal partners. It is a framework in which vulnerable minorities like disabled people, the emotionally ill and children can claim their share of the common heritage. Turner is right when he states,

citizenship is not simply about class and capitalism but also involves debates about the social rights of women, children, the elderly and even animals. The traditional debate is thus too narrow and requires elaboration and expansion. (Turner, 1986 : 11)

Heater (1990), Oliver and Heater (1994) introduces a significant contribution to the discussion on citizenship in enlarging the dimensions of citizenship by adding identity and virtue to the earlier list of civil, political and social. The three aspects highlighted by Marshall flow from citizenship as status. Identity, according to Oliver and Heater (1994) is a 'double-barrelled concept'. While it has a status implication, it is also part of

citizenship as feeling. It is basically the socio-psychological sense of belonging. Virtue relates to attitudes and behaviour namely the notion of being a good citizen.

The key issue in the disability perspective is the exclusion of disabled persons as members of the community. On the basis of a false construction of what is normal or abnormal, competent and incompetent disabled people are discriminated against as full members of society. Barton notes that

Citizenship involves the struggle for membership and participation in the community (Barton 1993 : 241).

and therefore disabled people are making a stand that they too, like others, are citizens. There are increasingly clear voices of disabled people questioning their oppression and segregation.

Jenny Morris, a disabled feminist, says:

we receive so many messages from the non disabled world that we are not wanted, that we are considered less than human (Morris, 1991 : 26 and 27).

Citizenship provides a useful theoretical framework for disabled people in confronting this segregation. In the Marshallian development it can be seen to extend political, social and civil rights to all sections of the population. This has been possible through the struggle for the extension of rights to excluded communities. Disabled people are now demanding these rights to be extended to them.

Oliver makes reference to Marshall's presentation of "citizenship as a means to the social integration of individuals into society" (Oliver 1993b : 11). It has been used

not simply to consider the social integration of the majority into society but also as a yardstick to measure the extent to which certain groups are not socially integrated. (Oliver, 1993b : 11).

Another dimension of membership in the community is to what extent does society at large create a barrier free environment for the integration of disabled people into mainstream community in order for disabled people to experience the reality of being full and equal citizens. This aspect of disabling barriers is one of Oliver's central themes, as it is these barriers which prevent disabled people from becoming citizens. An example he cites is language. The language of welfare and caring, argues Oliver:

serves to deny disabled people the right to be treated as fully competent, autonomous individuals, as active citizens (Oliver, 1993b : 22).

It is also seen as:

an inappropriate basis on which to develop a proper discourse of welfare provision and professional practice. (Oliver1993b : 23).

Language is seen as a political issue and related to empowerment. There is therefore the need to abandon patronizing and dependency-creating language.

In the context of disabled people's struggle for membership, Oliver identifies the disability movement as a new social movement. This is because he sees the disability movement in their struggle for power similar to other groups seeking to influence the political system like environmentalists, pacifists and minority groups. It is without doubt that the disability movement is now able to offer a political voice on behalf of disabled persons. In this context Barton (1993) emphasises that the growing collective self-confidence of disabled people should be enhanced and in this way the issue of institutional discrimination can be addressed.

4.4 Participation

Although Marshall noted that:

the political rights of citizenship, unlike the civil rights, were full of potential danger to the capitalist system (Marshall, 1950 : 96 and 97),

he is, however, accused by his critics of failing to articulate the struggle of the working class to bring about substantial improvements. Held (1989 : 193) observes that Giddens sees in Marshall's account an oversimplification of the role of politics and the state and therefore comes to Marshall's defence by stating that

when Marshall discussed citizenship and class, and when he described the relationship between the two as one of 'warfare', he was addressing himself explicitly to some of the major social movements which have shaped the contemporary world. (Held, 1989 : 194).

Turner (1990) developed a two-dimensional typology of citizenship, building on the work of Marshall and Mann. In the first case his focus is on the passive contrasted with the active depending on whether citizenship grew from above (via the state) or below (via grassroots participation). The second is a contrast between the public and private. He applies this typology to the historical development of citizenship in four types of democratic policies and countries namely Germany, France, England and the United States. Turner has therefore introduced into the citizenship discussion the struggle for participation whether passive or active from above and below. This aspect is helpful in reflecting the factors influencing participation of disabled people especially in the Malaysian context.

Barbalet notes the issue of the:

practical ability to exercise the rights or legal capacities which constitute the status of (being a) citizen" (Barbalet, 1988 : 2).

He points out that:

those disadvantaged by the class system are unable to practically participate in the community of citizenship in which they have legal membership (ibid.).

From this debate we can draw a number of lessons on the nature and place of struggle in the context of democratic participation. Firstly, there is the crucial theme of the role of the citizen and the state in creating a just society for all. In the past trade unions used collective bargaining as a means of attempting to raise the social and economic standards of their members. The citizen continues to have a responsibility to call upon the state to play its rightful role in ensuring a just life for all. The state in a parliamentary democracy is accountable to the citizenry.

Secondly, there is the principle of consumer participation or client empowerment. Based on the theory of citizenship, the clients or users of the services have rights. They are not to be in a dependent status and cared for in a paternalistic way but ought to be in a position of power and decision making on matters that affect their lives. Alongside these views is self-advocacy by people with learning difficulties, which is concerned with more than to

just have a voice in service, however important that is. It's also concerned with how we are treated and regarded more generally and with having greater say and control over the whole of our lives (Croft and Beresford, 1989 : 5).

It can clearly be noted that the citizenship principle emphasises the need for partnership and participation of clients in the planning and provision of services that affect their lives. In a sense the planners and providers of services are accountable to the clients or consumers of the services.

The framework developed by Doyal and Gough (1984) gives the opportunity to reverse the 'top down' approach not only in defining what are the needs but also in the allocation of

resources, as collective dialogue and collectively derived definition become central. The professional and bureaucratic approach which has thus far been dominant can be described as paternalistic in orientation. Doyal and Gough (1984) also acknowledge the desire and efforts of groups like the homeless people, single parents, tenants and battered women to define their own needs. Furthermore Croft and Beresford (1989) illustrate how

disabled people have developed a new politics of disability based on a critique of existing services, a redefinition of the problem and an attempt to create an alternative service structure controlled by disabled people themselves.(Croft and Beresford, 1989 : 11 and 12).

This discussion reinforces the theme of citizenship which envisages direct involvement in the political process through participatory politics. User involvement starts right at the point of defining what the needs are. Croft and Beresford affirm that,

it is this political process of gaining a say which we see as at the heart of citizenship (Croft and Beresford, 1989 : 16).

As we have already seen the key dimension is the fulfilment of human need which is not just a set of rights but also the power to realise it in reality, which

means offering people a voice in their society and social policy (*ibid.*)

The liberatory politics as described by Doyal and Gough (1984) cannot be passive. Founded on citizenship theory it must be allowed to play its responsible role in challenging the state and market structures of power. If these structures of power are not challenged there will only be transitory affects. Doyal and Gough conclude that

if struggles for more equal representation do not challenge the unfairness of the political and economic system, then they will inevitably fail to achieve what should be their real ultimate goal - the meeting of human needs. (Doyal and Gough, 1984, : 83).

Oliver makes a distinction between individual empowerment and collective empowerment. He reverses the emphasis from individual to collective empowerment as central and the starting point. In so doing he is critical of the recent discussions on user involvement and consumer participation as starting from the individual to the collective. He notes that the powerful do not share power or give it up. It is in this context according to Oliver that empowerment is the collective process on

which the powerless embark as part of their struggle to resist the oppression of others. (Oliver, 1993b : 24).

Oliver narrates the historical development of disabled people organising themselves as a collective power. Two key developments have wider relevance. Firstly, there is the need for disabled people to articulate the oppression they face. Secondly they need to develop organisations controlled by them. We return to this theme in Chapter Three.

4.5 Whose Responsibility - State or Market?

Do citizens have a moral right to their basic needs being met and is there an obligation on the part of those who process the resources to provide these? Plant (1988 : 53) identifies two responses in this context. The first is one in which welfare is a matter of charity, generosity and humanity and not of strict obligation. The recipients have no moral right to what they receive because no person can have a right to another person's charity. The second response identified by Plant is, welfare provision as a matter of strict obligation. Those who are in need have strict moral claims on those who hold resources. Their needs create a right to welfare and a duty on the part of the better endowed to grant welfare benefits to meet such needs. To Plant:

basic welfare is a human right to be claimed against the state and a strict obligation to be met by the state (Plant, 1980 : 72).

Therefore the theory of rights which corresponds with citizenship theory, provides the framework necessary for the needy to claim the necessary resources. Marshall, says Culpitt (1992), holds the assumption that it is the state which is responsible namely

a government cannot allow risk taking in welfare - or only minimally. It cannot leave any important part of its overall responsibilities in the hands of private agencies unless it takes steps to limit risk by regulation, supervision, inspection or safety nets. (Culpitt, 1992 : 82).

Mishra (1984 : 32) points out that to neo conservatives the idea of government failure is central to their evaluation of the post-war welfare state The New Right skilfully exploited the issue of social policy failures and has challenged the notion of absolute right without the fulfilment of obligations. They argue that welfare beneficiaries become dependent on welfare and are trapped within it. Charles Murray (1989, 1990) arguing from the right bears witness to the emergence of an underclass. In contrast Field (1989) writing from the left on the same issue of the new underclass points out that it is due to the new right policies and neglect of the State. According to Field the emergence of an underclass in Britain is no accident. This underclass largely comprises those dependent on minimum support who are unable to fit into the new enterprise culture. An attempt to set people free from dependency must take into account these structural issues.

Ruth Lister (1990a) rightly points out that the work obligations imposed upon the poor as a means of combating the dependency culture, has in practice meant that the poor end up with low-paid, unpleasant jobs. This reawakens the old issue of 'division of labour'. As we have already identified, citizenship is a dynamic concept and the motive of providing assistance must not enslave but liberate. The aim is to enable and empower individuals to function as responsible, self-reliant citizens, who will in due course enable others.

Ian Culpitt (1992) attributes the emergence of contracting policies in social service provisions to the shift in welfare paradigm described earlier, which is a major shift in social welfare philosophy. He notes that both contracting and privatisation are intimately linked. The traditionally held notion that the public is the preferred sector as opposed to voluntary and private sector as supplier of social services has been challenged and is being replaced. This paradigm shift notes Culpitt is as a result of the negative aspects of the state welfare bureaucracies which reflected a monolithic, paternalistic, authoritarian, ineffective and non-cost effective approach to welfare provisions.

In noting this paradigm shift Ian Culpitt (1992) draws three major points. Firstly, this shift in policy has had a radical effect and impact upon the role of community workers who are now popularly called 'care managers'. Secondly, Culpitt highlights how neo-conservatives have argued that contracting has the potential of reducing the overall financial burden of the government. Linked with this are the arguments for cost- effectiveness and delivery of better quality services. Thirdly, Culpitt highlights the crucial questions critics of this shift in policy and practice raise : what is the role of the State and function of the public sector? Culpitt (1992 : 108) notes two assumptions which underline this point. One is the assumption that the prime functions of state and public sector social services are to compensate for and redress some of the imbalances and inequities that exist in a typical welfare democracy. The second assumption is that the private welfare system is unable to act as a compensatory social device and that the creation of more equitable and just society will always require the state to be directly involved in the provisions of services.

David Taylor (1989), on the other hand, reveals how the marginalised have not been able to realise the liberal ideas through the false collectivism of the state or the consumerist democracy of the market because both have ignored the reality of power.

Both these ways of attempting to meet citizenship rights have led to the marginalisation of those excluded from the 'collective' nature of state welfare provision on the one hand, and of those unable to compete as market consumers on the other. (Taylor 1989 : 20).

Oliver's (1993b) major criticism on the theme of citizenship is with regards to state welfare. This is because while most would have expected state welfare to enhance the rights and position of disabled people in society the reverse is the case. In his assessment, state welfare has definitely not ensured citizenship rights for disabled people in Britain. It has however infringed and even taken away some rights. Linked with this aspect of state welfare notes Oliver, is the way welfare is currently based on a theory of needs as opposed to rights.

5. CITIZENSHIP DISCUSSION AND MALAYSIAN SOCIETY

At the end of a lengthy discussion on contemporary citizenship debates and some general reference to disabled people the matter we will examine in this section is the relevance and applicability of the citizenship discussion to the Malaysian context.

Malaysia is today a multi-ethnic, multi-cultural and multi-faith society. It has a population of 19.5 million and has three major ethnic communities namely the Malays and Indigenous people (59%), Chinese (32.1%), Indians (8.2%) and others (0.7%) (Malaysia, 1995a). Malaysia is currently undergoing a period of rapid socio-economic development and recording an economic growth of 8% since 1991 (Malaysia, 1995b). A brief historical

overview of citizenship developments will reveal how this nation came to being on receiving independence from the British on August 31, 1957.

5.1 Brief Historical overview on citizenship developments in Malaya

We now turn to the process where subjects in the land of Malay become citizens and how migrant communities also became full citizens. Suffian (1976) describes that federal citizenship was introduced by the 1948 Federation of Malaya Agreement.

Until then there was no common citizenship embracing the whole country, and a person was either a subject of a Ruler or if born in Malacca or Penang a British subject. (Suffian, 1976 : 251).

The introduction of the Malayan citizenship was in accordance with the Atlantic Charter which declared the right of nations to self rule, at the end of the Second World War, observes Andaya (1982). It was a citizenship which:

was to be extended to all without discrimination as to race or creed. (Andaya 1982 : 255).

It must be noted that there was an earlier attempt in 1946 when the colonial power introduced a citizenship plan under the Malayan Union Plan. However this plan failed as the Malay rulers and UMNO (United Malay National Organisation) opposed this scheme, which diluted the sovereignty of the rulers and Malay political identity. Sinnadurai (1978 : 70) observed that the effect of the 1946 proposal meant that the entire non Malay population would be accorded political rights and the Malays rejected this for fear of non-Malay domination. Ratnam discerns the difficulties as:

a conflict between Malay and non-Malay interests. The former are reluctant to dilute their political identity in a common 'Malayan' fold, and they fear the implications of placing the Chinese and the Indians on an equal footing with themselves. The non-Malays on the other hand, remain convinced that they should be given an equal share in the country's political life. (Ratnam, 1965 : 67).

Andaya (1982) describes the Chinese feeling as one of being betrayed. This is because the Chinese felt that they had sacrificed more and had been most loyal towards the British during the Second World War.

The British colonial masters appointed Lord Reid and his committee to prepare the Federal Constitution for an independent Malaya. What emerged out of this process is as Suffian notes 'a partnership agreement' (1976 : 342). Suffian also refers to the 'bargaining principle', namely the give and take and compromise of the major communities especially in the interest of national unity. He notes that:

the bargain that was struck between the representatives of the major communities was that in return for the relaxation of the conditions for the granting to non-Malays of citizenship, the rights and privileges of Malays as the indigenous people of the country were to be written into the constitution (Suffian, 1976 : 251).

The Reid commission faced the dilemma of balancing the interest of both the indigenous community and the non indigenous community preserving the single nationality with equal citizenship principle. We will return to the principle of positive discrimination and ethnic relations a little later in this chapter.

From the above discussion we can conclude that citizenship was introduced and the new nation was built on the premises of citizens rights and responsibilities, as enshrined in the Federal constitution. The implication being that a newly independent country like Malaya which received independence in 1957 even though historically and culturally non western was none the less, due to the colonial experience, introduced to a western based notion of parliamentary democracy and that therefore the new nation of Malaya with multi-racial, multi-cultural and multi-religious communities, should be based on the notion of citizenship rights and responsibilities as protected in the Federal Constitution. It was a partnership

agreement between the various communities. While the concept is alien to the context it can be affirmed that it is now here to stay and therefore requires some comparative analysis which is totally absent. This is because contemporary discussions focus on industrial countries neglecting the experience of developing countries.

In the Malayan experience of citizenship developments there has been ethnically based tension between the indigenous Malay population and the non indigenous migrant Malayan population of Chinese and Indians. The pluralistic context and ethnic relations between the majority Malay and the minority non Malay communities in how they accommodate to each others concerns is worth comparative analysis. Many other nations with a similar ethnic composition have not been able to resolve their differences on the basis of the citizenship framework as Malaysia has through a written constitution. Apart from one ethnic clash in May 1989 Malaysia has experienced relative racial harmony and political stability.

5.2 Relevance of Emerging Citizenship Themes

Turner (1993) in outlining a theory of human rights notes two important points. Firstly, he states that human rights is an important supplement to the existing idea of citizenship. This is because he feels that:

citizenship is often not an adequate mechanism for protecting individuals against a repressive or authoritarian state. (Turner, 1993 : 182).

Secondly, Turner (1993 : 176) states that citizenship appears to be historically and culturally specific to western culture, unlike human rights. The first of these comments will be discussed in the concluding chapter, but Turner's second observation will be addressed briefly here and more fully dealt with in the concluding chapter.

If we took the typology developed by Turner (1990) which was referred to earlier in this chapter, we can note that while the British sought to introduce the 1946 Malayan Union from above it was resisted by the majority indigenous community. However, what eventually emerged as a result of the consultation process undertaken by Lord Reid in the preparation of the Merdeka (Independence) Constitution, we can note the dynamic process of what emerges from below, an interactive process based on the 'bargaining principle' as Suffian describes it. There is a tradition within Malaysia that if a community felt strongly about it, it could highlight its grievance through a peaceful means for social change. What might emerge is not either one or the other demand but a healthy spirit of give and take, thereby resulting in a compromise solution acceptable to all parties concerned. This is therefore the dynamic process and outcome of the interaction between what is given from above and what emerges from below. In Turner's typology he develops water-tight categories which do not fit the Malaysian experience. What emerges is an interactive process between what is above or handed down and what emerges from below as well as between what is passive and active. In the Malayan experience the British were surprised by the protest made by the Malays to the Malayan Union which they did not anticipate because the Malay community were a peaceful people. What therefore emerges from the Malaysian experience is this dynamic process between the various communities to voice their concerns and seek joint political and social solutions in the interest of national unity and the welfare of all the people of the land.

In the earlier section we noted five major emerging themes from the contemporary citizenship debates. Some of these themes have relevance for the Malaysian context and in this section we will discuss them with specific reference to disabled people in Malaysia. Three points can be noted in this context.

Firstly, on the matter of rights, the Malaysian Federal Constitution makes no specific reference to disabled people. As we have noted the key discussion during the time of the writing of the Constitution centred around ethnicity, language, religion and culture. These were the key concerns of the early architects of Malaysia in the foundational years (1946 to 1957). In chapter Four reference is made to the legislative and constitutional drawbacks as seen by disabled people in Malaysia. However what is significant is that in recent years especially after the 1980s disabled people are making a claim to full citizenship in Malaysia and highlighting their experience of discrimination in Malaysian society. In doing so, John Kim, a blind disability activist, reiterates :

that the difference between the disabled and the rest of society is the unequal treatment. Such treatment has made the disabled feel cut off from mainstream society, thus making them second class citizens (John Kim, 1995 : 13)

Secondly, equality is a difficult concept to comprehend in Malaysia. While the Federal Constitution recognises that all the citizens are equal before the law, however Article 153 makes provision for the special position of Malays and at the same time Article 154 protects the interest of the non Malay community. Suffian explains the reason for the special provisions for the Malay community namely these:

protective provisions were written into the Malaysian constitution not with the intention of pulling back the advancement of the non-indigenous people but with the intention of securing the advancement of the indigenous people who, through no fault of their own, were and are educationally, socially and economically less advanced... (Suffian, 1976 : 321).

What is important to recognise within the Malaysian context is that, there is a historical precedent for positive discrimination in legislation and affirmative action which seeks to undo the social and economic disadvantages faced by the Malay community.

This experience compares with Marion Young's strategies to eliminate oppression as described earlier in this chapter. The Malaysian experience illustrates the effectiveness of affirmative action in uplifting the poor Malay community. The only point with regards to this aspect is that disabled people in Malaysia have not called for this affirmative action through a special position for themselves. We will return to this matter in Chapter Four, and later in Chapter Ten, when we discuss more fully the place of disabled people in Malaysian society.

Thirdly, the Malaysian model for welfare provision is a welfare pluralism model where different sectors for example the public, the voluntary, the informal (family) and the private sector play a part. This is a partnership model especially between the voluntary sector and the public sector to support the family unit in addressing social needs in the community. This can be noted as far back as 1946 (Annual Report, 1946) when after World War Two a Department of Social Welfare was established by the British colonial power. In the same year a Central Welfare Council was established to coordinate voluntary effort. Unlike the British welfare state no professional, bureaucratic system was established, none the less the dominant approach was a charity one. However the potential for the development of self-help groups and community based approach is strong as services are currently underdeveloped. This matter will be discussed more fully in subsequent chapters. What will emerge from the Malaysian context is policies and programmes for tapping the potential of the markets for the self-advancement of disabled people. Furthermore the role of the State in this process is being clarified especially in providing appropriate policies, monitoring mechanisms and financial allocations.

6. Chapter Conclusion

The key question to ask at this point is, what can we draw from the contemporary citizenship debates discussed earlier in this chapter which will form the basis for the formulation of a citizenship model of social work practice, as well as assist in the further exploration of this theme among disability theorists and activists internationally and with specific reference to Malaysian society. Five basic points can be summed up and these will be explored in the rest of this thesis.

Firstly, the citizenship framework of rights and responsibilities has the scope to ensure that disabled people are equal members of a community like any other people. However the detailed implications of this will undoubtedly have to be worked out.

Secondly, while civil, political, social and economic factors are essential elements of citizenship other dimensions related to status, economic security and psychological sense of belonging are also essential. It is important to recognise that an abstract declaration must be accompanied by practical experience for individuals and communities. Further study, analysis and appropriate action is needed where necessary to ensure that deficiencies in the policy and practice aspects are addressed. In this context, legislative protection is essential, so that disabled people can effectively claim the rights they have been denied until now.

Thirdly, along with rights there is an essential place for duties. However, here exercising those duties is understood as 'an active citizenship' in the new right sense. Instead it means empowering disabled people to play their rightful role as responsible citizens in nation building. Disabled people must themselves claim their rights and to this end appropriate

mechanisms must be in place to enable them to play that role. Much of these will be acquired through self-help and collective action.

Fourthly, the State has the responsibility to ensure that every citizen irrespective of race, gender, age, class or impairment has equal rights and opportunities in society. While this is guaranteed, it is however essential to note that the provision of services must be done in a plurality of ways rather than the conventional state welfare avenue. Affirmative action might be necessary to undo past experience of injustice and discrimination.

Fifthly, while Malaysia has a history and culture of its own, many of the key struggles faced by disabled people in exercising their citizenship are similar to those faced by people in other industrial countries. The dynamics of power in a capitalistic society where the disadvantaged are marginalised, sidelined and discriminated against is similar. Likewise attitudinal and environmental barriers experienced are also similar. Where there might be a difference is in the democratic space available for disabled people in Malaysia to voice their concerns and exercise their rights. This aspect will be dealt with more fully in Chapter Ten.

THEORIES ON DISABILITY AND PRACTICE IMPLICATIONS

1. Chapter Introduction

In chapter two we looked at the emerging themes of relevance to disabled people from contemporary citizenship debates. In this chapter we will focus attention on the different theories and models of disability with specific reference to the two-fold model (individual and social) developed by Oliver (1983, 1996). The attempt is to explore contemporary thinking among disabled people who are academics and activists and who have challenged traditional approaches to social work theory and practice among disabled people. In looking at the theories and models we also look at their implications through the study of innovations in practice. These innovations are built on the social model of disability which affirms and seeks to promote full citizenship of disabled people.

There is therefore this close link between the challenges made by disabled people to traditional rehabilitation and their demand for citizenship rights through the social model of disability. Len Barton (1993) argues that a disability perspective on citizenship ought to be based on a social theory of disability in which the voices of disabled people are central.

2. THEORETICAL FRAMEWORK AND MODELS

There are currently a number of well described accounts of disability theories and models among which the works of Bickenbach (1993), Vic Finkelstein (1993) and Oliver (1983, 1996) provide a helpful summaries.

Bickenbach (1993) develops a three-fold model of disablement, namely the biomedical model, the economic model and thirdly, the social-political model. Bickenbach provides a survey of the philosophical basis for social policy related to disability. Under the biomedical category the disabled person is referred to as a sick or injured person needing medical assistance. Under the economic category the cost benefit rationale is operational, namely, that the economic cost is taken into account. Finally the social-political model refers to the collective rights approach.

Vic Finkelstein (1993) developed a social death model, the social barriers model and advocates an administrative model. Finkelstein describes how the administrative approach dominates the way services are organised for disabled people. He is doubtful whether the social model can in itself explain the social aspects of the experience of disabled people.

Oliver (1983, 1996) on the other hand provides a two-fold model, namely the individual model and the social model. In developing a social model of disability, Oliver provides a critique of the individual approach which he also calls the personal tragedy theory of disability. This category also includes psychological and medical aspects of disability. He regards this as an inadequate and inappropriate model. In contrast he advocates a social model which according to him is a new paradigm shift away from physical limitations of individuals and personal inadequacy towards a focus on the physical and social environment. It is the environmental barriers which impose limitations on disabled people according to Oliver.

Oliver's two-fold model has been adopted as the framework in reconstructing the changes in theorizing about disability. This is because his two-fold model is comprehensive enough to incorporate the different dimensions identified by Bickenbach and Finkelstein. In response to Finkelstein, Oliver concludes that they both adopt a similar position namely a historical understanding which associates disability with the rise of capitalism. Furthermore Oliver clarifies two points regarding the usefulness of models.

Firstly, we must not assume that models in general and the social model in particular can do everything; that it can explain disability in totality. It is not a social theory of disability and it cannot do the work of social theory. Secondly, because it cannot explain everything, we should neither seek to expose inadequacies, which are more a product of the way we use it, nor abandon it before its usefulness has been fully exploited. (Oliver, 1996 : 41)

2.1 Individual Model of Disability

Two fundamental points according to Oliver describe the individual model of disability. This model firstly, locates the problem at the individual level and within the individual disabled person. Secondly, functional limitations or psychological losses are seen as the cause of the problem. Reference is made to this model being the personal tragedy theory of disability as well as an individual model in which there is a significant medical component.

The relationship between illness and disability in sociological writings can be traced back to the work of Parsons especially the 'sick role' model. Oliver aptly summarises Parsons position in noting that illness and disease are rooted in the assumption that they

impede both physiological and psychological abilities, 'sick' individuals are automatically relieved of all normal expectations and responsibilities. Generally considered unaccountable for their condition they are not expected to recover though their own volition. They are encouraged to view their present situation as 'abhorrent and undesirable', and, in order to regain their former status, are expected to seek help from professional medical experts. (Oliver, 1996b :4).

While the sick role is temporary, however the same assumptions are applied to disabled people as 'impaired role'.

The medicalization of a social problem is best noted in the context of people with learning difficulties where medicine has a dominating influence. This is discussed in detail by Joanna Ryan (1987). A number of points are made in this respect. Firstly, medicine and aspects associated with it namely, hospitals and their personnel have been the main instrument for excluding mentally handicapped people from society. Secondly, the appropriateness of the description and classification of different types and syndromes of mental handicap are questioned. Thirdly, while medicine dominates the field of medicine itself, mental handicap has a very low status. Fourthly, medical knowledge and medical care are of very limited benefit to mentally handicapped people. Finally:

many of the genuinely medical needs of mentally handicapped people are similar to those of the rest of the population, or to other disabled people, and there is a strong case for arguing that these should be met through the general health service rather than in specialist hospitals. What many handicapped people do need is support and training in their daily lives, and this is something the medical professions are particularly ill equipped to provide. (Ryan, 1987 : 18).

The individual model in practice implies that the major emphasis is upon physical and psychological adjustment of disabled persons. The issues raised by Wilding (1982) with regard to professional imperialism are utilised by Oliver to further establish his criticism of this dominant approach of social workers. This is because as social workers attempt to gain professional status they emphasised a medical, psychotherapeutic, individualised model of work as it seemed the best way of asserting their expertise and professionalism.

Based on a survey of different social writers on disability it is possible to classify their approaches under these two categories. It is important to note that even within these there are approaches which are more medical than others. In contrast some take the social context more seriously than others while still operating from within an individual framework. Colin Barnes (1996c) acknowledges that sociological writings of Erving Goffman (1961), Robert Scott (1969), Deborah Stone (1984), Wolfensberger and Gary Albrecht (1976) have contributed towards challenging the medical definitions of disability. However he notes that "they fail to examine some of the structural factors precipitating their application" (Barnes, 1996c : 3). In a similar way Oliver (1996b) notes that British medical sociologists, Blaxter (1976) and Locker (1985), as well as Fabian policy analysts Walker and Townsend's (1981) work are not located within critical or emancipatory theorising.

2.2 Social Model of Disability

The social model of disability challenges the individual model and its basic presuppositions. It is essential to note that it is disabled people and their movement who have creatively developed alternative thinking in theorizing disability in contemporary society. Finkelstein is right in his observation that:

new ways of interpreting disability arose directly out of disabled people's experiences when trying to influence the attitudes of service providers about the control and delivery of support systems. (Finkelstein, 1993 : 38).

In a similar way Zola (1979) notes that the Independent Living Movement (ILM) represented a direct challenge to rehabilitation. He said:

It is a unique challenge, spearheaded not by new technical advances but by a new social awareness, not by a new technical advances but by a new social awareness,

and not from within by medical personnel but from without by lay groups. (Zola, 1979 : 452)

Later in this chapter we will examine the ILM and the work of De Jong (1979).

In Britain, both Finkelstein and Oliver acknowledge the role played by Paul Hunt and the Union of the Physically Impaired Against Segregation (UPIAS). According to Finkelstein:

the UPIAS policy document marked a turning-point in understanding the meaning of disability. (Finkelstein, 1993 : 36).

Oliver too ascribes his conceptualisation of the individual and the social to UPIAS (Oliver, 1996 : 20). He acknowledges his indebtedness to the document especially in the way his understanding was shaped by it. He further states that Vic Finkelstein played a major role in producing the UPIAS document (Oliver, 1996 : 21).

Hunt was instrumental in the formation of UPIAS which eventually produced the document entitled 'Fundamental Principles of Disability' (Oliver, 1996 : 21-28). His experience as a Cheshire Home resident as well as his experience with the social researchers Miller and Gwynne firmly impressed on him the need for disabled people to articulate their issues and concerns. Along with other disabled people Hunt affirmed that they:

are tired of being statistics, cases, wonderfully courageous examples to the world, pitiable objects to stimulate fund-raising" (Hunt, 1966 : x).

Hunt rightly pinpoints the root cause of their problem as disabled people not in their physical attributes but in social oppression . He writes that

the social disabilities of oppressed groups are not a consequence of their physical attributes, but of forms of social organisation which discriminate against them. It is in fact those who create, maintain and justify the discriminatory forms of organisation who in reality are the main cause of our social disabilities or death sentences. (Hunt, 1981).

Oliver builds on the work of Paul Hunt, UPIAS and Finkelstein in giving depth to the social model of disability. According to Oliver the document states two significant points which have relevance in contemporary society. The first is the distinction drawn between impairment and disability. This has had its impact not only on the British Council of Disabled People (BCODP) but also in Disabled People's International (DPI) as both these organisations have adopted the UPIAS definitions. These have served to challenge the definitions formulated by the World Health Organisation (WHO) which is referred to later in this chapter. UPIAS defined impairment as "lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body" (Oliver, 1996 : 22). Disability on the other hand is defined as:

the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression. (ibid).

The second point Oliver makes about the relevance of UPIAS fundamental principles is the distinction developed between experts and amateurs and between organisations controlled by disabled people and those that are not.

Oliver describes the core of the social model by stating that:

it is society that has to change not individuals and this change will come about as part of a process of political empowerment of disabled people as a group and not through social policies and programmes delivered by establishment politicians and policy makers nor through individualised treatments and interventions provided by the medical and para-medical professions. (Oliver, 1983 : 53).

Oliver (1990) developed a materialist analysis based on a critique of capitalism as the basic cause of the social oppression faced by disabled people in industrial societies. He notes that

the rise of capitalist society and the reformulation of work patterns have facilitated the exclusion of disabled people from mainstream society. He explains an economic base for the creation of dependency based on how work was structured in industrial societies. He therefore concludes that :

disabled people are likely to face exclusion from the workforce because of their perceived inabilities, and hence dependency is still being created. (Oliver, 1990 : 86).

As a result they are made dependent upon public and voluntary assistance in order to survive. Furthermore Oliver states that:

the disabled individual is an ideological construction related to the core ideology of individualism and the peripheral ideologies related to medicalisation and normality. And the individual experience of disability is structured by the discursive practices which stem from these ideologies. (Oliver, 1990 : 58).

2.3 Social Model and its challenge to the medical approach

The social model of disability challenges the basic premises of the individualised medical and personal tragedy approaches. The problem is located within society, with its failure to provide appropriate services as well adequately ensuring the needs of disabled people are fully met.

The struggle is partly one of the relationship between illness and disability. As seen earlier medical sociologists and policy researchers see them as inter-related. However Oliver questions this. He notes that some disabled people might have illnesses which may have disabling consequences. This is not dismissed in the social model. Therefore some disabled people will have the need for the assistance of the doctor. However :

the problem arises when doctors try to use their knowledge and skills to treat disability rather than illness. Disability as a long-term social state is not treatable medically and is certainly not curable. Hence many disabled people experience

much medical intervention as, at best, inappropriate, and at worst oppressive. (Oliver, 1990 : 51).

Barnes' analysis (1996b) attacks the oppressive terminology used. He makes reference to the relationship between language, meaning and power. In the context of medicalization of disability his criticism centres around the International Classification of Impairment, Disability and Handicap (ICIDH) (WHO, 1980). Other disabled people including Oliver (1990), Morris (1993), and French (1994) have likewise been critical of ICIDH. In ICIDH classification, three terms are central namely, impairment; secondly, disability referring to restriction or lack as a result of the impairment; and thirdly, handicap which is the disadvantage faced .

Barnes (1996b) makes three critical comments. Firstly, that impairments are the primary focus as revealed from the basic assumptions of ICIDH which is based on intellectual and physical 'normality'. Secondly, medical intervention or a focus on 'cure' is seen as the appropriate intervention because impairments are seen as the main cause of disability and handicap. Thirdly, these definitions have been produced without reference to the international disabled people's movement. According to Barnes (1996b) the orientation adopted results in disabled people becoming objects to be treated, changed, improved and made 'normal'. These are therefore inappropriate as they 'medicalise and individualises' the problems encountered daily by disabled people.

It is the proponents of the Independent Living Movement who have made the greatest challenge to the medicalization of care. They advocate demedicalization which has

challenged medical professional dominance. De Jong (1979) dismisses the medical model, the sick role, and the impaired role. He affirms that:

the movement for independent living rejects the behavioral expectations created by both the sick role and its derivative, the impaired role, by saying that the disabled do not want to be relieved of their familial, occupational and civic responsibilities in exchange for a child-like dependency. In fact, this 'relief' is considered tantamount to denying the disabled their right to participate in the life of the community and their right to personhood. (De Jong, 1979).

2.4 Social Model and the critics from within the disability movement

There have been two main criticisms of the social model from within the disability movement, both based on disabled people's experience. These concern the relationship between impairment and disability, and cultural representation.

Firstly, the issue of the causal relationship between impairment and disability. Sally French (1994), Jenny Morris (1993) and Liz Crow (1996) argue that the experience of impairment has been neglected within the social model approach to disability. This is because the causal relationship between impairment and disability has been denied. Liz Crow (1996, forthcoming) develops the arguments further by thinking about impairment in three related ways. The first is in thinking of impairment as an objective concept as defined by DPI and UPIAS. Secondly, the subjective experience of impairment as experienced by individual disabled people and thirdly, the social context of impairment ie misrepresentation, social exclusion and discrimination. Crow affirms that these three layers are essential for understanding disabled people's personal and social experiences. She says that

we need to focus on disability and impairment: on the external and internal constituents they bring to our experiences. Impairment is about our body's ways of working and any implications that holds for our lives. Disability is about the reaction and impact of the outside world on our particular bodies (Crow, 1996: 6).

Suppression of the subjective experience of disabled people is not advocated by Crow, on the contrary her plea is for a recognition of the implications of impairment. Furthermore she advocates a holistic understanding of disabled people's experience.

Secondly, the issue of cultural representation. Tom Shakespeare (1994) describes this neglect of imagery within the social approach to disability. His main criticism of social model theorists such as Oliver and Finkelstein is that they have not devoted sufficient time to the question of meaning and representation. He points out that as disability is a complex issue it involves a number of causal components. The danger he highlights is the mono-linear explanations which reduce everything to economic factors. Shakespeare affirms that:

the social model needs to be reconceptualized: people with impairments are disabled, not just by material discrimination, but also by prejudice. This prejudice is not just interpersonal, it is also implicit in cultural representation, in language and in socialization. (Shakespeare, 1994 : 296)

Colin Barnes (1996b) recognises that Shakespeare's analysis, that the cultural roots of disabled people's oppression in western societies pre-date the emergence of capitalism may be a step forward. However he notes the draw back when all cultural responses to impairments are essentially seen in negative terms. This is because in certain cultures 'impairments' are positively perceived.

Other issues neglected by social model theorists are gender and ethnicity and the issue of multiple oppression. Oliver notes that these dissatisfactions have been expressed by disabled people:

not simply because the social model does not adequately reflect experience of oppression of all disabled people but also because it may simplify some of the issues. (Oliver, 1996 : 39).

2.5 The social model and its implications for social work practice

The theoretical discussions on the individual and social models have practice implications. Questions have been raised whether theory should be grounded in practice or practice in theory. It has been said that practical assistance to people in need is not theory based. Common sense and good will is sufficient in order to meet human need. Very often social work educators have failed to establish adequate links between theory and practice. Practitioners, on the other, hand have found the irrelevance of theory for actual practice and involvement. The general argument is 'let us get on with the job'. The issue is further complicated:

because social work has no knowledge base of its own. We have had to borrow most of our ideas from the social and behavioural sciences which give only general explanations of social life (Coulshed, 1988 : 5).

Both Coulshed (1988) and Howe (1987) see the importance of theory for practice. According to Coulshed one of the chief reasons for writing a book on this theme is the conviction that theory improves practice. Howe affirms that it is not easy to dismiss theory. He argues

that not only is theory in social work unavoidably integral to any practice, but also its relegation to an implicit, unarticulated status leads to poor, indeed dishonest practice. (Howe, 1987 : 1).

Neil Thompson in developing anti-discriminatory social work practice acknowledges that:

understanding of the underlying conceptual framework, and the themes and concepts of which it consist, is necessary to ensure that such practice is based on intelligent and informed debate, rather than dogma, fad or ignorance. (Thompson, 1993 : 14).

In stating this he notes that social workers occupy positions of power and influence. He therefore notes the importance of taking seriously into account issues such as class, gender, race/ethnicity, age and disability into account in formulating a practice:

which seeks to reduce, undermine or eliminate discrimination and oppression. (Thompson, 1993 : 31).

While the individual model sees the role as adjusting individual disabled people to their disabling condition, the social model challenges this by addressing the issues of a disabling environment. It is a practice which challenges the:

barriers which exclude disabled people from full active citizenship. These barriers can permeate every aspect of the physical and social environment: attitudes, institutions, language and culture, organisation and delivery of support services, and the power relations and structures of which society is constituted. (Swain, 1993 : 2).

The social model of disability challenges traditional models of practice namely case work, group work and community work. However the changes in practice as a result of the market oriented strategies introduced in Britain also signal the irrelevance of traditional approaches. Oliver states that:

social work of whatever kind and using which ever method, is no longer seen as being relevant to the needs of disabled people. (Oliver, 1991 : 14).

It is however still necessary to review the implications for two reasons. Firstly, the market changes and introduction of case or care management do not have relevance in Malaysia where practice is still influenced by traditional social work methods namely case work, group work and community work, with an increasing emphasis on community work from a social development perspective, similar to other developing countries. (Midgley, 1981, 1995). Secondly, as Celia Doyle (1994) indicates while the language of the market and business is used for case management, there are still relevant parallels between case management and case work especially in the areas of making assessments in order to inform the purchase of care.

Oliver's (1983) comments on social work are helpful, as he makes reference to casework, groupwork and community work methods. With regard to casework he affirms that the switch from an individual to a social model of disability, does not imply the death of casework rather, casework is seen:

as one of a range of options for skilled intervention. It does not deny that some people may grieve or mourn for their lost able body but suggests that such a view should not dominate the social worker's assessment of what the problem may be (Oliver, 1983 : 28).

In groupwork, too, there can be a reorientation away from a therapeutic environment in which individuals or families come to terms with disability. Groups can be reorganised to enhance self-help in sharing information and support. Likewise groups can be used as the major means of giving disabled people back responsibility for their own lives especially in the residential care context. In the case of community work the possibility is cited for developing a people's movement through forum meetings. The understanding of the community is shifted beyond the geographical setting to "communities of interest". The focus is to mobilise disabled persons to articulate the issues and confront the authorities on the basis of their rights.

Oliver (1993) gives an indication of the way forward in social work practice. Three principles are helpful. Firstly, there is a need to move away from the delivery of health and personal services through professionalised bureaucracies towards a system where there is a greater participation of disabled people in the provision of services. The heart of the struggle is who should be in control and the call is for new forms of professional practice. This implies an altering of professional practice to enable disabled people to be in control. Secondly, there is a need to change practice from the management of the patient to that of

the worker being a resource person to disabled people. Thirdly, there is a need to create organisational structures which facilitate the same shift in responsibility.

3. INNOVATIVE DEVELOPMENTS IN PRACTICE

In this section, five innovative developments in practice are cited. In these examples the focus is on general principles relevant to the theme of citizenship and the social model of disability rather than the detailed description of practice approaches. These examples show that practice based on a social model perspective and undergirded by citizenship is possible.

There are a number of similarities among the five examples cited below. There is a similarity in emphasis as the central focus is upon enabling disabled people to have a greater say and control over their lives and the services they need. This can be clearly noted at the levels of identification of need. The assessment is not made by professionals alone but together with the disabled person. Strategies formulated for addressing the need are likewise organised with the disabled person in a form that is acceptable. The affirmation of the human dignity and human rights of disabled people is clearly noted in all the approaches. One major difference in this context is that the movements like the Independent Living Movement in the United States were strongly influenced by the civil rights movement and were therefore far more aggressive in asserting their rights in comparison to the Community Based Rehabilitation Programme (CBR) as practised in developing countries. While the CBR is a major step forward in comparison to traditional institutional based rehabilitation it operates within the cultural climate of non aggression. This could be seen as a reformist attempt from within whereas the ILM is more radical at both the conceptual as well as the implementation level. However it would be wrong to

conclude that one is more effective than the other. There is a need to appreciate the contextual dynamics. Both attitudinal and environmental barriers in developing countries are being challenged through the CBR programmes as noted by Peter Coleridge (1993). This aspect is further discussed in Chapter Four when we discuss the approaches adopted by disabled people in Malaysia in bring about social changes within their context.

In reading through these innovative examples six foundational principles can be deduced which have direct relevance in the formulation of a citizenship model of social work practice from within the social model of disability. Firstly, in all these examples the potentials of disabled people are tapped. In so doing there is an affirmation that disabled people like all other human beings have the capacity to take charge of their lives. Secondly, there is a clear emphasis on the leadership development of disabled people in taking charge not only of their individual lives but also their movement. This process starts with the self awareness of their disadvantaged position which is not to lead them into inaction but to challenge them for dynamic direct action in making the changes necessary in society. Thirdly, the principle of participation is essential. This is strongly emphasised in all the examples namely that the disabled person is not a passive recipient of services. Participation and involvement in all aspects of life in the community is central.. Fourthly, the ownership of the programme or project is crucial. Unlike the traditional approach where ownership is elsewhere, in all the examples described in this section ownership is by disabled people themselves or in partnership with the community. Fifthly, what is altered in these examples is the role of professionals who do not serve as experts but as resource persons and co workers. Sixthly, the effective end result of these examples is not only

disabled people regaining their self confidence and self respect but the enhancement of their autonomy and independence in life.

As indicated earlier the purpose of highlighting these innovative examples is not to provide a critical assessment of their successes or failures but to draw out the significant underlying principles which may prove useful in the formulation of a citizens model for social involvement.

3.1 Independent Living

The Independent Living Movement (ILM) in the US and the UK has made the most radical attack on the incarceration experienced by disabled people in residential homes by providing alternative models of living in the community. The research work done by Miller and Gwynne (1972) on Le Court Cheshire Home reveals not only the bias of researchers but also the ideological flaws of those administering residential provisions for disabled people. They concluded that:

to be admitted to one of these institutions is to enter a kind of limbo in which one has been written off as a member of society but is not yet physically dead.(Miller and Gwynne 1972 : 80).

The role of the institution is to cater for the socially dead during the interval between social death and physical death.

According to De Jong (1979) disabled people in the ILM in the US equated their experience with that of the civil rights movement. They saw environmental barriers depriving them from participating in the political life of the community.

Central to the goals of the movement for independent living is the belief that the management of medically stabilized disabilities should be demedicalized. Disabled persons are insisting that the management of their disabilities is primarily a personal matter and only secondarily a medical matter. A constant medical presence in the lives of disabled persons is said to entail behaviours on the part of both medical practitioners and disabled 'patients' that induce dependency and thus are in conflict with rehabilitation and independent living goals. (1979 : 244).

While these positive affirmations and directions are made by disabled people through the ILM, Gareth Williams's (1988, 1989, 1991) criticism of the underlying ethos of the movement needs to be taken into account especially as the movement operates within the free-market pluralist ideology in an attempt to :

reclaim their own lives through reasserting their autonomy in opposition to state controlled monopolies(1988 : 1004).

While Williams acknowledges the movement's drive for enhancing self-reliance through consumer power, his main concern is with the impact of shrinking national budgets. Furthermore he questions De Jong's political theory where free and equal persons compete for resources and especially the individualistic assumptions adopted.

While the dangers that Williams is highlighting in the course that the ILM has undertaken may be noted, it is essential to remember that from within the State oriented services disabled people did not experience their liberation. Therefore the markets have provided an avenue for consumer choice and voice. What Williams failed to recognise is that while the ILM operates within consumer choice it has also adopted a civil rights and self help orientation which takes legislation seriously. Therefore, citizenship rights are advocated through legislation namely in areas such as discrimination and architectural barriers. Furthermore, as De Jong himself notes, disabled people must have the 'right to choose for

good and evil' and therefore only when they have the possibility of failure can they have achieved true independence.

With the change from institutions to the community one would conclude that the issue of institutionalisation is irrelevant in the UK. However in the study made by Jenny Morris (1993) it can be concluded that the social death ethos can be dominant even in the community context ie 'institutionalisation within the community'. Her key question is whether impairment itself creates dependency or whether it is society's reaction to impairment which creates dependency. She rightly refers to a difference between to 'care about' someone and to 'care for' someone. She concludes that the ideology of caring is one which is associated with taking charge of, in the sense of taking responsibility for them. In her analysis this approach is basically the custodial nature of caring which dominates residential and institutional settings. It is, however, reappearing in community care through reliance on informal care and domiciliary care. In her analysis the independent living movement is challenging these assumptions and approaches.

Morris (1993 : 21) identifies four basis assumptions which provide the philosophy of the independent living movement. Firstly, that all human life is of value. Secondly, that anyone, whatever their impairment, is capable of exerting choices. Thirdly, that people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives. Fourthly, that disabled people have the right to participate fully in society.

Independence does not mean that one does everything oneself. However in this context it would be having the control over the assistance or support provided. Jenny Morris (1993 : 174 - 175) provides some pointers which have general application for practice. Firstly there is a need to reclaim the words 'care' and 'caring' to mean 'love', and 'caring about', rather than 'caring for', with its custodial overtones. Secondly, when someone receives physical assistance, whether from a paid worker or a partner or relative the service providers need to think about how disabled people's control over their lives can be promoted. There is a need to guard against over-protectiveness. Thirdly, there must be a shift to assessment based on needs rather than that determined by the type of services available. Self-assessment and advocacy services could have a key role to play in resisting the financial and organisational pressures to resource-led assessment. Fourthly, the development of organisations controlled by disabled people which can play a part in influencing public and independent sector organisations to deliver services in a way which gives choice and control to the consumer of their services.

3.2 Supportive model

Gerry Zarb (1991) develops what he calls a supportive model of social work where a supportive environment is developed in contrast to a disabling environment. While he develop the approach within a very specific context, namely meeting the needs of people who are ageing with a disability an attempt is made to draw general principles which could be applied in a wider context. An example cited is the Grove Road model where residents in a small community provided support to their disabled neighbours on a mutually arranged basis. What this example provides is:

a very important practical illustration of how various supportive resources which people might wish to use could be organised in order to provide choice and security. (Zarb, 1991 : 200).

It is further important to note that the common principle underlying the kinds of arrangements made (ie either through local statutory services, supporting families, local voluntary groups, neighbours or selective hire of agency nurses), is that they are built around ordinary lifestyles. This is contrasted with the approach of :

forcing people to fit into a 'structure' of support provision which requires them to organise their daily lives around the way in which particular services are provided. (Zarb, 1991 : 201).

The model centres around meeting needs in a supportive way ie enabling people to live independently. Four general principles are drawn from the model developed by Gerry Zarb. Firstly, the provision of supportive services should be made on the basis of rights. Secondly, the emphasis of a supportive way is upon self-defined needs of people wanting support as opposed to needs defined by professionals. The focus is upon disabled people having control over how their support needs should be met. Personal autonomy should be preserved. Thirdly, there is often the tension between fixed options offered by social welfare agencies and people's needs. These available options might not necessarily meet the needs of the disabled person. What is thus required in any social work intervention should be the development of individuals' ideal solutions to their own support needs. There is thus a call for flexible support provisions. Fourthly, there is the need for creative solutions. Support should be geared towards enabling people to move towards the attainment of their own solutions; building on the resources they already have and, if necessary enabling them to define and implement appropriate solutions through the provision of an adequate and flexible choice of supportive resources and living options.

3.3 Participation model

The foundational principle in a practical guide for social change and involvement formulated by Peter Beresford and Suzy Croft (1993) is citizenship. They acknowledge that "citizenship is a helpful concept for exploring involvement because it is essentially concerned with people's participation as members of society" (1993 : 4). This philosophy of people's participation underpins the policy for citizen involvement. It is concerned with enabling people's broad-based involvement. Both Beresford and Croft affirm that by involving people it is possible to develop appropriate and accountable services. These services are neighbourhood based with structures that are not only able to meet needs but are democratic and accountable. The concern of Beresford and Croft is:

not only with challenging the oppression and inequalities that people face, but also doing this in a way which fully involves them. People's involvement is both the end and the means. (Beresford and Croft, 1993 : 6).

The notion of citizen involvement is closely linked with empowerment. A distinction is made between empowerment and consumerism.

The starting point of one is our rights and responsibilities as members of a society. The second is more narrowly concerned with us as individualised recipients of goods and services. The idea of empowerment is particularly linked with supporting those who are most disadvantaged and disempowered. (Beresford and Croft, 1993 : 19)

Beresford and Croft use the terms 'empower' to mean making it possible for people to exercise power and have more control over their lives. That means having a voice in institutions, agencies and situations which affect them. It also means being able to share power, or exercise power over someone else, as well as them exercising it over you. The central critical concept of empowerment for practice is the issue of power. Beresford and Croft refer to 'a new paternalism' which draws attention to an 'unequal balance of power'

which generally exists between services and citizens. They highlight the thin line between setting up user groups and colonising them.

User-involvement is already being staked out as another sphere for political, professional and research intervention. We've read articles by senior managers telling user groups what to do and how to organise. Conferences are organised as user participation and empowerment, but service users aren't necessarily involved in their planning. (Beresford and Croft, 1993: 125).

There is therefore a real need to examine the opportunities provided and the nature of involvement in order to ensure genuine participation.

Four important dimensions to an empowering practice are developed. They describe a practice which puts people in a position to have more say and offers first and foremost concrete expression of their involvement. Firstly, the aim of practice is to empower people. This means challenging oppression and discrimination. It is also enabling people to take greater charge of their lives. Secondly, practice offers people control in their personal dealings with agencies - allowing them to participate in what happens to them instead of being kept in an excluded or passive relationship. Service users should be involved in assessment, planning, recording, action and review. Defining their own needs and having a say in planning and decision-making. Thirdly, practice equips people to take power, enabling them to participate by helping them gain the confidence, self-esteem, assertiveness, expectations, knowledge and skills needed to have an effective say. Fourthly, the agency in which practice is located must be open to people's involvement, therefore offering opportunities, structures and resources for a say in its working. The focus of this approach is in seeking to empower people and developing people's involvement and partnership.

3.4 A self-help model

Both in the United Kingdom and the developing countries there is a rich heritage of self-help. In the UK it was especially so in the nineteenth century as a response to the industrialisation process (Gosden, 1973). However a number of factors weakened self-help during the twentieth century. One reason cited by Green (1993), is the coming of the welfare state from the reforms of the 1909 -1914 Liberal Government to the post World War Two Labour legislation after World War Two. There is now however a rise of self-help groups especially in response "to perceived shortcomings in medical and other professional services" (Oliver and Hasler, 1987 : 115). In the self-help groups of disabled persons cited by Oliver and Hasler, members are encouraged towards both individual as well as collective self-help responses. They are encouraged to solve their problems themselves and not have them solved for them.

In the Asia and Pacific region the regional United Nations office has been doing much to encourage the development of self-help groups of disabled people. Self-help is understood to mean:

mutual support and empathetic human relationships. It is group solidarity which enables disabled people who are experiencing similar hardship to support each other and to overcome common difficulties through the exchange of practical information, insight and knowledge gained through personal experience. That solidarity and mutual support serves as a basis for collective action to improve the existing situation of people with disabilities in society. (ESCAP, 1991a : 11).

These self-help organisations can be characterised in three ways. Firstly, self-determination and control by self-motivated disabled persons. Secondly, self-advocacy for equal opportunities and full participation. and thirdly, mutual support mechanisms ie peer counselling. There is therefore the need for both the public and voluntary providers of

services to foster the development of self-help groups and tap the potential of disabled people.

It is significant to note that self-help in nineteenth century Britain can be conceived as an alternative to collective political actions to achieve some reforms. Perhaps the distinctive thing about contemporary self-help organisations is the way they combine information sharing, brokerage and sometimes supply of services to members with collective political action.

3.5 Community Based Rehabilitation (CBR)

The World Health Organisation (1976) introduced the community approach in 1976 in developing countries where there were insufficient facilities. This approach is opposite to institutional care and segregation. CBR aims at:

reducing the impact of disabling and handicapping conditions, and at enabling the disabled and handicapped to achieve social integration. Rehabilitation aims not only at training disabled and handicapped persons to adapt to their environment, but also at intervening in their immediate environment and society as a whole in order to facilitate their social integration. (WHO, 1981 : 9).

In contrast to institutional care, CBR involves the community and the resources within it are tapped for the programme.

In a study undertaken by Peter Coleridge (1993) in six developing countries, he makes some significant links between citizenship and development. He notes that the CBR approach is community based with people participation and is developmental in orientation. He provides some useful insights not only for disability work but also in extending the citizenship framework among disabled people. It is significant to observe that many points

identified in developing countries are also featured in the experience of disabled people in industrial countries. Firstly, he notes that the starting point, is to differentiate between charity and development, welfare and development. Charity and welfare according to Peter Coleridge does not challenge or change the status quo but perpetuates it. On the other hand development is not only about people understanding the causes of their underdevelopment but seeking to do something to change it. Secondly, what disabled people want is their rights as ordinary citizens to be recognised. Coleridge cites Joshua Malinga, the President of Disabled People's International, affirming that:

disabled people want to be treated as normal citizens, with rights. They want to be treated equally and participate as equal citizens in their own communities. To achieve this you need political and social action to change society. (Coleridge, 1993 : 54).

Thirdly, the existing provisions are welfare oriented. The way the projects are designed even if they are community based often tends to treat disabled people as recipients rather than participants in the decision making process. It is therefore essential to facilitate an active role of the service users rather than to perpetuate the passive role of recipients. Fourthly, a development approach is one which enhances the potential of disabled people and recognises that they are human with all the economic, emotional, physical, intellectual, spiritual, social and political needs that other people have. By development it also means the involvement of disabled people in the planning and implementation of services and enables them to play a leading part in this process. Furthermore a development approach implies 'human resource development' which implies,

developing people, enabling disabled people who are psychologically stunted and disempowered by social attitudes and religious prejudices.(Coleridge, 1993 : 17).

Fifthly, the community worker in this context has the role of :

enabling and facilitating other people and fostering a climate of mutual trust and cooperation. (Coleridge, 1993 : 90).

Sixthly, whatever form the service delivery takes:

unless disabled people themselves play a key role in its design and delivery, working together with able-bodied people, then it will not empower disabled people. (Coleridge, 1993 : 92).

Seventh, that disability is an issue which demands basic rights to be recognised by the State. The role of the State is to provide comprehensive public policies which take into account disability issues and concerns in their macro socio-economic planning.

The development approach further enhances contemporary citizenship discussion. Participatory development principles can enhance the integration of disabled people in the decision making process. Community development experience has shown that neglect of consultation and participation of affected people has resulted in project failures. Participation is noted as the main prerequisite for sustainable development. (Clark, 1991 : 56).

4. CITIZENSHIP MODEL FOR SOCIAL WORK PRACTICE

Emerging out of our discussion in Chapter Two on citizenship and in this chapter on disability theories, a 'Citizenship model for social work practice' has been developed taking into account many of the practical considerations raised thus far. It establishes the essential generic principles upon which a social work theory and practice, as well as a voluntary agency policy and structure can be developed. These will serve as guiding principles of the subsequent enquiry into social work practice among disabled people in the Malaysian context from a citizenship perspective. The citizenship model is presented in this section

in an outline form. However the citizenship model will be critically reviewed and reformulated in Chapter Ten in the light of the findings from the Malaysian field study.

This model is divided into five parts starting with some general principles in the first part. The second and third parts deal with social work theory and practice. Voluntary agency policy and structure are the focus of the last two parts. Thus, a comprehensive framework is developed drawing out the practical implications of the discussions on citizenship and disability theories. Views expressed by disabled people in the literature previously reviewed are taken seriously into account.

4.1 Guiding Principles

Disabled people as citizens

Disabled people are fellow human beings who have inherent rights and dignity. By virtue of being human they share the same rights as fellow human beings and citizens of the nation. Disabled people have political, civil, social and economic rights as citizens of the nation. All injustice and oppression restricting their realisation of these goals must be removed. Disabled people are not to be discriminated against by virtue of their impairments. The rights based approach also affirms the duties and obligations of citizenship. In this context citizens with impairments will have opportunities to play their part in nation building.

Rights and not charity as the foundation

In accordance with rights of citizenship, disabled people must not be viewed as objects of charity but must be accorded rights to equal opportunities and equal shares in the resources

of the land. On account of this principle the services provided must be comprehensive and universal, meeting the needs of disabled people on the basis of citizenship rights.

National development agenda

Disability concerns must be incorporated into macro-socio-economic planning processes and national development programme for example in education, employment, industry, health, housing, transport policies. This approach will ensure that the rights of disabled people are taken into account in order that they too will benefit from economic growth and development rather than being sidelined.

Citizenship guaranteed by comprehensive legislation

Due to the experience of discrimination, there is the crucial need for appropriate legislation, for the protection and enforcement of these rights. Constitutional inclusions as well as new legislation needs to be enacted in order to ensure the desired outcomes.

Welfare pluralism

It is affirmed that while the State is to ensure and safeguard the citizenship rights of disabled people, a plurality of service providers is needed in order to consolidate the position of disabled people in main stream society namely the role played by the public sector alongside the voluntary, informal and private sectors.

4.2 Social Work Theory

Central to social work practice is theory and therefore the starting point here is to develop an appropriate theory based on the foundations of the above guiding principles.

Social model of disability

The citizenship model of social work can only be built upon the social theory of disability, as disability is not an individual problem based on personal tragedy. The social oppression faced by disabled people due to the disabling environment must not only be taken seriously into account in developing social intervention programmes but must be the focal point of action.

Empowerment

Empowerment is allowing and enabling disabled people to take control. It is a process which enables disabled people to explore the extent of their potential and overcome their limitations set by the negative attitudes of society. It is primarily enabling and enhancing the capacity of the people to determine their own future.

Developmental in orientation

A developmental orientation facilitates a client-centred or people centred perspective ie taking the views of disabled people seriously and also seeking to understand their views, concerns, and how they define the situation.

4.3 Social Work Practice

Practice, based on an appropriate theory as stated above will facilitate the empowerment of disabled people. This is the goal of practice to empower disabled people as citizens with full political, civil, social and economic rights.

Reorientation and organisation of social work task

Social work must be re oriented and organised in order to ensure that the primary task is to help them work alongside service users, their families and the local community in order to help them explore and express their needs and define the support they need. Programmes developed must enhance the positive self-image of disabled people as well as develop analysis skills for social change and community mobilisation.

Reorientation of case work, group work and community work

There is a place for all these three approaches for practice. Case work must take into account the wider social issues in the individual assistance provided. The goal is one of empowering the individual person. The focus of group work should centre upon self-help and mutual aid as this will enable mutual support. The key approach for citizenship is community work where the disabled person is not only integrated into the community but will be able to experience the mutual support of the community. This is not a one way process as disabled people receive the supportive assistance of the community, they too play a part as members of the community. Community awareness and education is crucial to remove the disabling environment created by false and negative attitudes. Involvement in public policy formulation and advocacy is essential in addressing structural and environmental barriers. Therefore the ultimate aim of whatever approach or method used whether in day care, respite care, independent living units, vocational training, educational, employment services, is to ensure that disabled people are in control and their potential enhanced. Creating dependency of any kind must be avoided.

Reorientation of the role of social workers and professionals

The citizenship model seeks a renewed role for social workers and professionals not as experts but resource workers, facilitators, and enablers working alongside disabled people. The social worker moves from helper in control to enabler, resource worker and advocate working in collaboration. Social work training likewise must be reoriented to affirm the central role of disabled people in their rehabilitation.

4.4 Voluntary Agency Policy

Central to the empowerment of disabled people is that all the different sectors in the mixed economy of care or welfare pluralism must develop agency policies which will enhance the citizenship rights of disabled people.

User involvement policy

The direct involvement of disabled people in the identification of needs, planning for social intervention, resource allocation and evaluation is central to the citizenship model of social work. User involvement and control are the twin policies for voluntary agencies working alongside disabled people. This becomes the yardstick for the evaluation of the agency's commitment to the rights of disabled people. Involvement must be seen not only at the level of elected officials but also in employment as staff in the agencies. Encouragement and opportunities must be created to facilitate power sharing especially in voluntary organisations. A clear policy on this matter must be made public along with a plan of action to ensure the materialisation of the policy.

Consumer and Public accountability

Agencies whether public, voluntary or private must be accountable to disabled people and their organisations, by making information available especially on service users ie assessment and resource allocation, as well as on financial matters.

Leadership development

Organisations must have a stated policy which give a clear course of action to develop leadership potential of disabled people. Both formal and informal training opportunities must be organised for human resource development.

4.5 Voluntary Agency Structure

It is without doubt that ideal policies must have mechanisms for their effective realisation. This is where a rethinking of agencies' structures is crucial. The structure must enhance and facilitate the participation of disabled persons.

Decentralised organisational structures

In order to facilitate effective participation of disabled people in the organisations that provide services, attempts must be made to decentralise the structure. By this it is intended that the structure will enable the maximum participation of many disabled persons as possible. Membership means an opportunity to share in the operations of the organisations. Decentralisation rather than a centralised approach will facilitate this process. The attempt is to avoid bureaucratic structures which disempower service users.

Bottom up decision making process

Related to decentralisation is the decision making process. A centralised approach facilitates a 'top down' decision making mechanism which resembles an authoritarian approach and discourages active participation. However in keeping with citizenship principles a 'bottom up' process with maximum consultation and involvement will give each person a sense of self-worth and belonging.

Small organisational structures

In order for people to feel a part they must belong to a smaller group ie neighbourhood groups, interest groups, where relationships can be fostered and developed. Everyone will feel a sense of belonging. There is an urgent need to facilitate the development of self-help organisations where disabled people take the lead and facilitate group formation. However, just to focus on the micro will be self-defeating as there is also a macro dimension. In order to capture the balance, networking and co ordinating agencies should be established or reorganised to make the necessary links at the district, national, regional and global levels.

5. Chapter Conclusion

In this chapter we have examined the popular disability theories with specific reference to the social model of disability as developed by Oliver and noted its practical significance. Guidelines for a citizenship model for social work, theory and practice as well as agency policy and structure were formulated in an outline form. This will serve as a useful framework in examining the experiences of disabled people in Malaysia. This model is reformulated in Chapter Ten in the light of the field study findings and analysis.

Emerging from the discussion on citizenship in Chapter Two and the disability theories in this chapter, two broad approaches available to disabled people can be noted in how they can experience empowerment in this contemporary age. These approaches can operate as two separate and distinctive approaches or there could be a balance and integration between them both. One is the approach which enhances participation, group solidarity and collective action through the political process though not necessarily in party politics. In this approach the aspect of VOICE is central where disabled people have a voice through direct action to claim their right in society. The other is the CHOICE approach through the markets where disabled people exercise their consumer rights. Here opportunities are enhanced through mutual-aid. These approaches seek to empower disabled people and both these avenues of VOICE through the political process and CHOICE through the markets will be explored and dealt with more fully in Chapter Ten.

DISABLED PEOPLE AND MALAYSIAN SOCIETY

1. Chapter Introduction

The attempt in this chapter is to provide a macro analysis of social policy and service developments in Malaysian society with specific reference to disabled people. Earlier in Chapter Two when we discussed citizenship issues, some pointers with regards to the constitutional development of citizenship rights were noted in general in the Malaysian context. In this chapter relevant policies and legislation either affirming citizenship rights or the neglect of it for disabled people will be highlighted. More clearly what will be illustrated is the Malaysian model of welfare pluralism where the State provides a climate for the development of social and welfare oriented voluntary organisations. The nature of the welfare society or caring society in Malaysia is discussed. Furthermore in line with our discussion on disability theories in Chapter Three, opinions of Malaysian disabled people will be highlighted to provide a Malaysian disabled people's perspective on matters affecting them in the Malaysian context. These will be further elaborated in the field study analysis as described in Chapter Six, Seven Eight and Nine. What is interesting to note is that disabled people in Malaysia have experiences and concerns which are very similar to those of disabled people in the West but at the same time there are differences in analysis and strategies adopted for social change. In many ways this chapter sets the context for further exploration on the theme of citizenship and social work in Malaysia. This comprehensive overview is also helpful in understanding the role of voluntary organisations in providing social programmes for, with and among disabled people.

Although much of the theoretical discussion on citizenship and disability models is drawn from Britain, it is however beyond the scope of this thesis to provide a comparative analysis of social policy provisions in Britain and Malaysia. It is possible to note some similarity of experiences but there are glaring differences in policy, provisions and strategies adopted to influence the policy process. Therefore this chapter avoids a comparison of provisions with Britain but provides an analysis of the Malaysian provisions in the light of the citizenship theme.

Organised social work among disabled people in Malaysia could be divided into three periods, as developed by Jayasooria and Ooi (1994). The first period was the institutional care period (1940 - 1960) during which time institutional services were set up and this was the dominant approach. The next period was between 1960 - 1980 which saw the emergence of disabled peoples self-help organisations. In the third period from the early 1980s, community based services developed with a clear change in approach from institutional care to community based rehabilitation programmes. It is, however important to note that these three periods are not watertight periods, as there are some overlaps in the developments. In each period only significant developments are highlighted. The developments do not mean that the features of one period are overcome by the new developments as all the different features still exist to this day. However what has changed is the emphasis and direction adopted.

We will begin the enquiry of services provided by the State, voluntary and self-help groups by firstly critically examining the appropriate policies relevant to disabled people in Malaysia.

2. NATIONAL POLICIES AND LEGISLATION RELEVANT TO DISABLED PEOPLE

There are references made in a number of existing policies and legislations which have relevance for disabled people in Malaysia. It is important to note that policies are basically general directives and all concerned are encouraged to respond appropriately. In contrast legislation provides for greater protection as there are legal requirements to be fulfilled as well as implications to deter non compliance. There is a greater tendency in Malaysia to rely on political pronouncements and incentives rather than legislation and punishment as in the case of employment of disabled people, described in this section. It is, therefore, appealing to the moral conscience and good will, especially of the business community, rather than making it a legal requirement. This definitely reveals the state Malaysia is in, indicating that social welfare for disabled people is hardly a matter of rights but dependent on the good will of the rest of the community in ensuring a society for all its citizens.

Another important dimension is the impact on the Malaysian policy and social programme formulation process of the international instruments, policies and programmes formulated by the United Nations as in the International Year of the Disabled Persons (IYDP), the regional office the Economic and Social Commission for Asia and the Pacific (ESCAP) and in the Asian and Pacific Decade of Disabled People. This external input both at the international and regional level has, according to disabled people in Malaysia, contributed towards their well being. One could conclude that the policies formulated by the UN and ESCAP provide a form of check list with which National programmes in developing and newly industrialising countries could be examined, compared and emulated. The UN and ESCAP operates on a consultative process and therefore the policies, especially those promoted by ESCAP, are

making a positive contribution to comparable developments in the future. Malaysia has participated in all the recent ESCAP Expert Group Meetings with a representative from the Department of Social Welfare and a disabled person from a voluntary or self-help organisation.

2.1 National Policies of relevance to disabled people

There are two national policies which have relevance to disabled people. The first is the National Welfare Policy which describes the nature of caring in general in Malaysian society. The second is the Policy on Employment for disabled people in the private and public sector. The National Welfare Policy provides the foundation to the Prime Minister's challenge in 1991 on establishing a caring society and caring culture as part of the overall vision of Malaysia becoming a fully developed nation by the year 2020. The National Welfare Policy (1990) is a brief, comprehensive statement which identifies the goal, aim, strategy both general and specific, and implementation guidelines. It gives a brief description of thirteen target groups needing assistance, one of which is disabled people. The overall goal is to produce a secure and stable society. Its three-fold strategy is significant for policy and practice namely to create self reliance, to equalise opportunities for the less fortunate and to foster the spirit of mutual help and support towards enhancing the caring culture. The theme of self reliance and equal opportunities is basically a strategy of developing resilience in individuals and communities. While the policy identifies six urgent tasks namely the need for cooperation to utilise community resources and development of social welfare, integration, training of workers, research and effective leadership, it fails to indicate who will be responsible for them.

The policy is the most clear statement made by the Malaysian government on the nature of the caring society. It has been popularised in the media as a result of the political endorsement and therefore serves as the foundational principles on the theme of fostering a caring culture and society. Furthermore academic review and support was established when a leading social and economic 'think tank', The Institute of Strategic and International Studies (ISIS), organised the First National Conference on the Caring Society in 1990. (Cho and Salleh, 1992).

However there is a major draw back to the Policy Statement, which in the long run might not facilitate equal opportunities for disabled people in Malaysian society. The orientation of the policy is towards seeing needs and problems at an individual level with the emphasis on self-reliance or on developing the human potential. In taking this approach the inference is that disabled people are not in mainstream society because they have not taken advantage of the economic development and therefore as Oliver (1983, 1996) defines it approaches the problem from within a focus on individuals. While the policy indicates equal opportunities it does not adequately address the issues of attitudinal, environmental and institutional barriers.

In 1989 the Malaysian government announced that 1% of the jobs in the public sector will be reserved for disabled persons. In the following year (1990) it was extended to the private sector. While this is not mandated by legislation, tax incentives are provided to the private sector in order to encourage them to provide job opportunities. The Ministry for Human Resources has been playing a leading role in popularising this policy. A National Committee for the promotion of employment of disabled persons in the private sector was formed by this Ministry (Ganapathy, 1992). One of its first programmes was the launching of a campaign to

promote the employment of disabled people. Three incentives are provided for the private sector to employ disabled people (Chong, 1993). Firstly, deductions in respect of expenditure on the provision of any equipment to assist a disabled employee. Secondly, double tax deductions in respect of the remuneration paid to each employee who is physically or mentally disabled. Thirdly, double deduction on expenses incurred in the training of any handicapped person.

While these policies have been largely political statements rather than a clearly articulated and formulated policy, they do provide the policy opportunity for future development. There is an urgent need for a clearly thought out policy with guidelines for its effective implementation and monitoring. Nevertheless the direct involvement of the Ministry of Human Resources is a major breakthrough for disabled people. This involvement is breaking down the old stereotype which implied that matters pertaining to disabled people should be handled by the Department of Social Welfare. The concerns of disabled people are now, at least in a small way, being addressed by the Human Resources Ministry which is responsible for employment related matters for other Malaysians citizens.

The success of policy initiatives along lines of quotas through legislative provisions have had mixed success in other countries. In Britain, The Disabled Persons (Employment) Act 1944

gave disabled people legal rights to employment [and] ... placed an obligation on all employers employing more than twenty workers to employ a quota of 3 per cent of the work-force who were registered as disabled. (Oliver, 1983:108).

However in practice there is widespread evasion by employers and lack of enforcement by the appropriate authorities. Oliver rightly, notes that

despite these legal rights it remains true that disabled workers are more likely to be unemployed than their able-bodied counterparts. (*ibid.*)

2.2. Legislation with reference to disabled people

Wong Teck Meng (1981) draws reference to seventeen statutes which have some direct or indirect reference to disabled people in Malaysia. However, he notes that only the Workmen's Compensation Ordinance (1952), and the Employees Social Security Act (1969),

come near to the realm of the rights of the disabled by providing monetary benefits to those who are disabled during the course of employment. (Wong, 1981 : 71).

These have relevance to those who have been in the labour market and become disabled during their course of the work become disabled.

Jayasooria *et al* (1992), Ooi (1994a) and Lim (1993), provide a brief reflection on the implications of the Federal Constitution for disabled people. The basic conclusion is that disabled people could not claim their rights on the basis of the current provisions in the Federal Constitution. Constitutionally, a disabled person might perhaps claim his/her rights based on Article Eight of the Federal Constitution but not without modification. This Article in clause one affirms that 'all persons are equal before the law and entitled to the equal protection of the law'. Clause two however qualifies this by stating there shall be no discrimination against citizens in the ground only of religion, race, descent or place of birth'.

Tun Suffian (1976) a retired Lord President of the Supreme Court of Malaysia, clarifies that:

the discrimination which is based solely on the ground that the person discriminated against professes a particular religion, belongs to a particular race or is of particular descent or was born in a particular place, and **on no other ground**. (emphasis by the researcher). (Suffian, 1976 : 216).

He goes on to state that

if there is any other ground or consideration for the differential treatment apart from those prohibited by the article, the discrimination will not be unconstitutional". (Suffian, 1976:216).

It is clear that disabled people in Malaysia cannot assert their rights on the basis of the Federal Constitution. There is therefore the need to incorporate into Article Eight constitutional protection for disabled people.

The Uniform Building By-Laws 1984 under the Street, Drainage and Building Act 1974 were amended in 1990 to provide facilities for disabled people. According to Esther Lim a disability activist and lawyer this is

the major breakthrough for the disabled and the first step towards overcoming the environmental and structural barriers.(Lim, 1993).

Under the amendments all new public buildings will have to provide facilities for disabled people and owners of existing buildings have three years to make adaptations. A working committee was set up by the Ministry of Housing and Local Government, on the initiative of the Ministry of National Unity and Social Development, to draw up a code of practice for access to public building. The Malaysian Standard 1184:1991⁶ 'Code of Practice for access for disabled persons to public buildings' was released by the Standards and Industrial Research Institute of Malaysia (SIRIM). This Malaysian Standard specifies the basic requirements for elements of buildings and related facilities so as to permit access by disabled people. These requirements are applicable to all buildings that disabled people may use as members of the general public either as visitors or for the purposes of employment. The second 'Code of Practice for disabled people outside buildings is still in the process of completion. Under the Act it is the Local Authorities who are required to ensure its smooth implementation. However

the Uniform By Laws and the Standard Code have to be firstly gazetted by all the State authorities, only then will it be obligatory for the developers to take into consideration the needs of the disabled when planning the construction of public facilities. Even prior to the enactment of these, Goh Ban Lee (1992) had called upon Local Authorities under The Town and Country Act and the Street, Drainage and Building Act to "play a more positive role in bringing about a caring society" (Goh, 1992). Thus far only six of the thirteen States and one of the two Federal Territories have gazetted these two new provisions for disabled people. In addition there are difficulties with monitoring the legislation as well as a lack of understanding by town planning officials of the specific needs of disabled people. The major problem is with regard to implementation and monitoring the By-Law in order to ensure effective implementation.

Both Esther Lim (1993, 1995) and Godfrey Ooi (1994a) call for more legislative protection for disabled people. In Esther's analysis a two-fold strategy is appropriate namely in the first stage to provide laws "for the minium basic rights of disabled persons" with a parallel public awareness programme. Only in a second stage

when the country is ready to accept greater responsibility can more elaborate legislation be provided for" (Lim, 1993 : 23).

Esther Lim recognises the importance of legislative measures when she draws a difference between charity and rights in the context of measures to protect disabled people She notes:

To be charitable is seen as a positive trait in most cultures. However, it is often - even through not always - unreliable in the long run and on a scale not large enough to achieve what is needed. It is the legislative measures that can effectively protect the rights of persons with disabilities. It is through establishing the necessary legal basis so that other measures to assist the disabled could rely. (Lim, 1995:3)

She is optimistic

that a concrete foundation has been laid for the erection of an effective legal framework to safeguard the disabled" (Lim, 1993:24).

Godfrey clearly calls for the introduction of a

national disability legislation as a necessity in order to protect and ensure the rights of the disabled as equal citizens of the country"(1994a).

These calls are similar to those made by disabled people in Britain (Barnes, 1991; Barnes and Oliver, 1995). Barnes and Oliver call for a comprehensive legislative policy

which emphasizes civil rights rather than individual needs and focuses on the disabling society. (Barnes and Oliver, 1995 : 114).

2.3 International (UN) and Regional (ESCAP) Policies

Since the 1981 International Year of Disabled Persons (IYDP) the United Nations through its World Action Programme (1983-1992) has been playing a part

to assist policy-makers, planners, legislators, etc., to adopt disability policies and to provide a time frame for the initial implementation of the World Programme of Action. (Barry, 1992:1)

In the assessment that Mamadou Barry (1992) made, he highlighted some apparent achievements over the decade, three of which are significant. Firstly, redefining disability issues in a human rights context, secondly, increased public awareness of disability issues, and thirdly, disabled people through their organisations have been able to increase their influence. The major draw back he notes in most developing countries is that there has been a lack of comprehensive planning as well as insufficient funding which reflects the low priority given to disability issues. Rafeeuddin Ahmend (1993) in describing the positive outcome of the decade acknowledges :

the emergence of a global movement recognizing the importance of the integration of people with disabilities into society as a means of building 'societies for all'. This outcome was a significant departure from a long-held perception of people with disabilities as medical cases and objects of charity, towards one focusing on people with disabilities as citizens, community participants and family members.(Ahmend, 1993 : i).

Godfrey Ooi (1994b) in his assessment of the impact of the IYDP in Malaysia notes three significant aspects. Firstly, Malaysian society has come to the realisation that they have the responsibility that "disabled people are no longer relegated to the dumps of silence and despair". (Ooi, 1994b). Secondly that the plight and struggles of the disabled have been highlighted and thirdly that disabled people in Malaysia have realised that they have an important role to play in society. According to Ooi:

1981 has become an important landmark in the history of disability work for our disabled people [as well as] the water-shed between the past and the future with regards to disability work in Malaysia. (Ooi, 1994b : 2).

Furthermore he acknowledges that the Malaysian government has taken cognisance of the UN pronouncements and documents pertaining to the disabled. Over the past ten years or more explained Godfrey Ooi,

we have seen greater interest on the part of the Government in providing for the needs of the disabled in such things as the national budget, public awareness and even representation of the disabled on various committees. (Ooi, 1994c : 5).

Chandra Muzaffar (1989 : 17) in his analysis is more critical and raises the question of how many people in general in Malaysia and in particular in the Malaysian Parliament, know about the UN Declaration on the rights of disabled people. In noting this he implied that there is still a lack of understanding on the fundamental issues. He calls for the popularisation of the declaration on rights of disabled people. It is important to note that Malaysia has not ratified this declaration.

While we note the positive impact, we can also acknowledge that more needs to be done. At the surface level there is a political endorsement of the UN decade but, as one looks deeper within, much more needs to be done in order to ensure the equalisation of opportunities for disabled people. However the United Nations in general and its regional office Economic and Social Commission for Asia and the Pacific (ESCAP) have been systematically and consistently monitoring as well as further developing in specific ways the agenda of the World Programme of Action. At Beijing, China in 1992 ESCAP proclaimed the period 1993-2002 as the Asian and Pacific Decade of Disabled People. An Agenda for Action for the Asian and Pacific Decade of Disabled persons was also adopted. This was adopted because there was concern that in the region which has the worlds largest number of disabled people, the region had not adequately responded to the challenges of the UN decade. Therefore the promotion of full participation and equality of disabled people in the Asian and Pacific region which is the theme of this regional decade is an appropriate one. Malaysia was represented at this gathering and agreed to ratify the proclamation. On May 16, 1994 the Deputy Prime Minister, Dato' Seri Anuar Ibrahim signed the proclamation on behalf of the Malaysian government. This is indeed a positive step forward for Malaysia and on the foundations of the UN decade, the policies of the regional decade will be consolidated.

It is further important to note that the Asian and Pacific Decade has been formulated in accordance with the 'Social Development Strategy for the ESCAP region Towards the year 2000 and beyond' (ESCAP, 1991), which was adopted by the Fourth Asian and Pacific Ministerial Conference on Social Welfare and Social Development, held at Manila in October 1991. Malaysia was represented at this gathering which has adopted a three-fold strategy for the region namely eradication of absolute poverty, realization of distributive justice and the

enhancement of popular participation. These policy statements and strategic plans address disability issues from a social perspective. It is formulated on the basis of rights of all disabled people through the enactment of appropriate legislation. It addresses essential aspects such as public awareness, accessibility and communication, education, training and employment. A major strategy for implementation is the establishment and strengthening of self-help organisations of disabled people including associations of advocates and families of disabled people.

Since the proclamation of the Asian and Pacific decade a number of expert group meetings have been organised in the region. Three are notable as they focus on the heart of the current challenges namely: appropriate legislation (Malaysia,1993); matters pertaining to non-handicapping environments (Philippines,1994); and issues relating to self-help groups and organisations of disabled people (Thailand,1994). These have been attended by Malaysian delegates from the Government and disabled people's movement¹. The documents that have emerged from these gatherings will have an eventual impact on national governments in the region for appropriate action. Furthermore the role ESCAP is playing in the region continues to remind the governments of their role in enhancing the equal opportunities of disabled people.

Three recent documents² (UN, 1993 a,b,c) released by the United Nations provide a

¹Esther Lim presented a paper at the Consultative Expert Meeting on National Disability Legislation for the Asian and Pacific Region, Dec.6-8, 1993, Kuala Lumpur, Malaysia. Godfrey Ooi presented papers at the other two gatherings,East and Southeast Asia Workshop on Management of self-help organisations of people with disabilities, Jan.18-27,1994, Bacolod City,Philippine and The Expert Group Meeting on the Promotion of Non-Handicapping Environments in the Asian and Pacific Region, June 6-10,1994, Bangkok, Thailand.

²These three documents provide foundational principles for developing countries develop appropriate policies based on these. 1993a provides guidelines for equalization of opportunities. 1993b on legislation likewise provides a framework for developing countries to adopt for national use 1993c are guidelines on the development of organisations of disabled people which was prepared with the assistance of Vic Finkelstein.

comprehensive framework for National governments and disabled peoples movements to use it the basis of developing appropriate policies and concrete plans for local action.

3. STATE SERVICES FOR DISABLED PEOPLE

Jayasooria (1993) indicates that in the Malaysian experience, the State entered the arena of social services as a 'reluctant provider'. Sushama (1985, 1992), Baginda (1992), Zaharaha Awang (1992) and Jayasooria (1993) note that State intervention was necessitated by the aftermath of the Japanese occupation. As revealed in the 1946 Annual Report on Social Welfare, the Colonial rulers only recognised their role after the Second World War and provided 'institutional relief' for persons disabled through chronic illness, blindness and loss of limbs. The Department of Social Welfare was established in 1946. Prior to this period there was no organised welfare by the colonial officials. Welfare was organised and supported for a majority of the people at the informal level mainly by the family. Voluntary organisations established by Christian missionaries, also ran institutions for orphans, the disabled and the aged. These were in existence before the war and carried on their operation during and after the war. The reluctance of the colonial government was addressed at The South East Asian Social Welfare Conference organised by the Colonial office in 1947. At this conference it was recognised by all the delegations that social welfare is a function of government' (Minutes, 1947).

One of the principle duties of the newly formed Department of Social Welfare in 1946 was "the care of the crippled, blind and feeble-minded" (Annual Report, 1946 :11) and one of their earliest projects was the establishment of Jubilee Home, a residential centre, in 1953. Jayasooria and Ooi (1994) indicate that this early period can be characterised as the

institutional and custodial care period. Services were provided for disabled persons in institutional settings where residential care, educational and vocational training were provided. Due to the institutional nature it segregated disabled persons from mainstream society. The charitable attempts during this period did not empower the disabled for participation in decision making, policy formulation, resource allocation and service provision. Disabled people were viewed as mere recipients and therefore the service providers did not prepare disabled persons for active involvement and leadership roles.

It is essential to observe, as Susahma (1985), Zaharah Awang (1992), Jayasooria (1993) have done how the UN Conference of Ministers responsible for Social Welfare, held in 1968 at New York, made a significant impact in the orientation, direction and structure of social welfare programmes in Malaysia. Susahma (1985 : 216) observed that while the traditional responsibilities remained, new attempts in prevention and social development were introduced. It is striking to note that this conference affirmed the responsibility of governments towards welfare and spelled out the framework for social services namely the:

availability and accessibility of social welfare services as a right to the entire population, equally in urban and rural areas, on the basis of equality and non discrimination' (UN, 1968 : 7).

There is therefore a broader concept of social welfare that emerged in 1968 moving beyond the remedial to prevention and development orientations.

Since the early years significant development has taken place. While different government agencies (for example the Ministry of Health, the Ministry of Human Resources and the Ministry of Education), have a part to play in providing services to disabled people, the major role is played by the Ministry of National Unity and Social Development in general and in

particular the Department of Social Welfare. Certain services are directly administered at the Federal office in areas of policy development, training and running of institutions (Ariff, 1993) and others are run by the State offices in areas such as direct grant provisions and co ordination of the community services (Rahman, 1995).

3.1 Registration and Terminology

The Malaysian government estimates that 1% of the population have some form of impairment (Sayed Rahman, 1995). This figure was derived from a sample survey on 5% of the population conducted by the Social Welfare Department between 1958 and 1959 in order to ascertain the extend of disability among the population. Since then the Malaysian government has adopted this figure and no other Government sponsored national survey has been conducted to further ascertain the prevalence of disability. Four other localised field studies have been conducted in Malaysia (Chen, 1983; Halim, 1983; Osman Ali, 1989; Ooi, 1989). However these have not been conclusive to determine a national figure and therefore Malaysia continues to adopt the 1% figure, as opposed to the World Health Organisation's estimate of 10% (WHO, 1981). With a population of 19 million this will mean 190,000 disabled people based on 1% or 1.9 million based on 10%.

Disabled people are not an homogenous group and in Malaysia the government recognises four main categories and the terms used are the blind, deaf, physically handicapped and mentally retarded. Medical categories and terminologies are in dominant use. As in other developing countries a majority of disabled people in Malaysia have impairments which are birth related, congenital, or acquired in early childhood (Tugwell, 1992). In recent times

however disabilities acquired through industrial and automobile accidents are on the increase (Jayasooria *et al.*, 1996).

The Department of Social Welfare is responsible for keeping a register of disabled people. As Wong Sui Leong rightly observes

the figures as compiled by the department of social welfare Malaysia obviously do not reflect the actual disability situation in the country. This is because registration is voluntary (Wong, 1992 : 1).

Although the department has conducted campaigns to encourage registration however a majority of Malaysians are not coming forward to register. Culture and stigma could be the basic inhibitor.

Figures released on the registered number of disabled people, reveal the tremendous short fall in comparison with the estimated numbers based on either 1% or 10% of the Malaysian population.

Table 1: Registered number of disabled people

CATEGORIES	KLANG VALLEY December 1995 figures	NATIONAL FIGURES June 1995 figures
Blind	1, 511	10,416
Deaf	1,889	19,358
Physically Handicapped	3,340	10,197
Mentally Retarded	3,910	15,702
	10,650	55,673

Source: Department of Social Welfare (1995)

It is in this context that alternative suggestions (Jayasooria *et al.*, 1992 :245) have been made to remove the stigma upon families by two possible ways. Firstly, a register of disabled people should be maintained and updated at a central registry administered by the registration department rather than the Department of Social Welfare. Secondly, all general hospitals and private maternity homes should report the birth of disabled children. Likewise disabilities caused after birth should also be reported by the relevant bodies concerned.

3.2 Institutional/ Residential care and Vocational services.

Institutional care has been seen in the past as the key service provided by the Social Welfare Department to disabled people who have been abandoned by their families. Five institutions are run by the department providing long term care to 706 people with learning difficulties in 1994.(Department of Statistics, 1995:280) One of these institutions is situated in the Klang valley. The care provided in these homes has had some public debate when the media revealed abuse of the residents. Pictures of naked children who were tied to their beds were published by the Chinese newspapers and later circulated by the Reuter's news agency. The Minister concerned in a press statement said in response

I assure the public that the Ministry is doing its best to help these people; it is unfortunate that the inmates have to be tied up but it is for their own safety. (Star,1991).

The Ministry has been defensive and have not accepted the fact that the real reason for these people with learning difficulties being tied up is the lack of staff, especially those who are well trained to provide creative living skills programmes oriented towards independent living. These events have motivated the Department of Social Welfare to establish group homes as an alternative programme towards deinstitutionalising the disabled people. Five group homes have been set up by the Department catering for about 26 persons.

Since 1966 the Department of Social Welfare has been running the Cheras Rehabilitation centre which provides training and accommodation for 120 physically disabled people. It is situated in the Klang valley. The vocational training includes areas like tailoring, radio and T.V. repair. The aim is to train and develop the potential of disabled people. According to Zainul Ariff (1993), since 1966, 1,600 physically disabled people have completed their training. Another sheltered workshop for the physically handicapped situated in the Klang valley is the Bengkel Daya Klang which also provides employment opportunities. Under the 6th Malaysia Plan an Industrial Training and Rehabilitation Centre will be established at Bangi at the cost of RM 37 million. This centre will provide retraining for those disabled through accident as well as catering for those disabled from birth. The training facilities will cater for 350 disabled persons in fostering industrial skill related to contemporary times.

These sheltered workshops have been established in response to the realization that there are many disabled people who face difficulties in competing for job opportunities in the open market. Such sheltered workshops provide viable alternatives as they are built on the positive premise that the disabled have an important role in generating wealth and contributing to the country's economic growth despite their disabilities (Sayed Rahman, 1995a : 13)

Tugwell (1992) advocates the mainstreaming of vocational training as opposed to specialised centres set up exclusively for the disabled. This is the position recommended by the International Labour Office as reflected in their documents. It reads:

wherever possible, disabled persons should receive training with and under the same conditions as non-disabled persons. Special services should be set up or developed for training disabled persons who, particularly by reason of the nature or the severity of their disability, cannot be trained in company with non-disabled persons". (ILO,1970: 99)

In this context Tugwell, highlights the role of the social welfare department and voluntary agencies should play namely:

to ensure the accessibility of mainstream training to disabled people, to offer social support services to the disabled undergoing training and, where necessary, advisory services to the training centres in helping to develop easy use of these facilities. (Tugwell, 1991 : 9).

3.3 Financial and equipment support to disabled people.

Disabled people and their families could apply for help from the general assistance scheme available. This is a basic residual provision and it is given on a means test basis rather than by right of citizenship. Under the general welfare assistance programme families qualified for the financial aid are those earning less than RM300 a month. The assistance includes a family assistance scheme of RM 150, youth undergoing training assistance of RM 80 and schooling assistance to RM 50. Aid to old folks is Rm 70.

A number of direct grants and support are also available to disabled people. Three notable ones are: firstly, a business grant of RM2,000.00 is available for a disabled person beginning a business. Secondly the work incentive allowance of RM50.00 is given to a working disabled person earning between RM20 - RM300 in order to encourage the person as well as topping up the income. Thirdly, funds are provided to purchase equipment like wheel chairs or hearing aid.

In 1992 according to Zainul Ariff (1993), 327 persons received equipment grants totalling RM 239,810 and 1992, 109 disabled people benefited from the business grant scheme. While these are good examples there are a number of problems. Firstly, they are granted on the basis of need rather than right. Secondly, the amount provided is insufficient. The amount provided when compared with the Poverty Line Income (PLI) will reveal the true picture. The PLI is set at Ringgit 405.00 per month for a household of five (Malaysia,1995) and hardcore poor

are 50% of this figure. It is estimated that about 143,100 households or 4% (Malaysia, 1991) of the total households are in hardcore poverty. However there are no figures nor research done to indicate the level of poverty of disabled people in Malaysia. Nonetheless one can conclude that a majority are in a disadvantaged position. We will return to this point later in Chapter Ten. The funds available through the Department of Social Welfare are insufficient to enable them to lead a life out of poverty if they do not have a well paid job, the assistance of their family or voluntary agency. Thirdly, the number of those benefiting from the current services provided is insignificant even in relation to the total number of disabled people registered

3.4 Educational Services

Kamariah Jalil (1993) provides a comprehensive description of the educational programmes available for disabled people. She highlights that an Inter-Ministerial Committee on Education which met between 1981 and 1983, and formulated a policy of understanding among the different roles different Ministries and Departments will play in the education of disabled people. The Ministry of Education is responsible for the formal education of disabled people under four categories. Firstly disabled people who are visually impaired, secondly, those with hearing impairment, thirdly, the orthopaedically handicapped and finally the educable mentally retarded or persons with mild learning difficulties. The educational programmes are provided through special schools and special classes. There are a total of 141 programmes with 5,100 students and 748 teachers in 1993 under the direct purview of the Ministry of Education. The Department of Social Welfare is responsible for providing non formal education to those who could not be fitted to normal schools, special schools or special classes in normal schools. Therefore the Department of Social Welfare took charge of the severally mentally handicapped

and the multiple handicapped in rehabilitation programmes in day centres or in the community through CBR.

A positive step forward was the formation of A National Advisory Council on Children with Special Needs in 1991. It provides a platform for joint action among the relevant government agencies as well as the voluntary sector in providing education. However as it is only an advisory council it falls short of ensuring the effective implementation of educational programmes which are so urgently needed by children with learning difficulties.

Educational provision for disabled people falls far short of the needs and demands. While education is free in Malaysia in the primary and secondary school, for all Malaysian children, it is not compulsory. Therefore there is no legal requirement for comprehensive provision. Apart from the reference in the Education Act 1961, section 25 on the provision of special schools at the discretion of the Minister, there are no safe guards to ensure that education is provided as a matter of right to disabled people in Malaysia.

3.5 Employment Services³

As indicated earlier there has been much emphasis on encouraging the private sector in providing employment opportunities for disabled persons. There have been attempts both by the Department of Social Welfare and Human Resources Ministry to foster employment opportunities. It is estimated that only 10 to 20% of the 89,000 disabled people who can be

³ Three Seminars have brought employment related issues to the forefront of Malaysian society. They are: Seminar on Education and Training of the Handicapped and their integration into the labour market (Oct.27-28, 1992, Kuala Lumpur); Seminar on the Role of the Private Sector in the socio-economic upliftment of disabled persons (Nov.11-13, 1993, Kuala Lumpur) and National Seminar on Vocational Rehabilitation and Employment of the disabled (Dec.11-12, 1995, Kuala Lumpur). The researcher participated in all three and in the third presented a paper.

considered to be economically active are earning a living or are self-employed (Ganapathy, 1992). In an attempt to address this need, the Ministry of Human Resources set up a National Committee for the Promotion of Employment Opportunities for disabled people in the private sector. By the end of 1991 about 744 disabled people were employed in the public sector. In appeals made by the Ministry of Human Resources between 1990 and 1991 a total of 2,152 jobs were offered by the private sector. However only 1,249 were taken by disabled people between 1990 and 1993. (Ganapathy, 1992)

Ganapathy (1992 : 1) identifies five reasons for insufficient takers. Firstly, the absence of a register of job seekers among disabled persons. On the part of both Government and voluntary agencies this is not well co-ordinated. Secondly, the prejudice against the disabled. Thirdly, the poor access to public facilities. Fourthly, the location of employment, as 70% of the jobs offered were located in the Klang valley and fifthly, the reluctance of employers to modify or adopt machinery and facilities for the disabled.

In order to enhance the untapped potential of disabled persons in the workplace there is an urgent need for skilled placement services on a nationwide scale. This service must not project a welfare or charitable image and as Tugwell says:

should have more in common with the world of personnel management than that of social work. (Tugwell, 1992:11)

The placement officer must fill

the role of honest broker, acting objectively in the best interests of both the employer and the job-seeker. The placement officer is the 'market maker' bringing together the demand and supply. (*ibid.*)

Ganapathy (1992) like Tugwell, places the setting up of the placement services on a high priority. Jayasooria *et al* (1996), likewise affirm that both the Ministry of National Unity and Social Development, and the Human Resources Ministry set up professional placement services nationwide and network with both the private and voluntary sector. Jayasooria *et al* (1996) further note that employment and vocational training for the disabled cannot be considered in isolation from other factors such as educational opportunities and issues related to accessibility.

3.6 Community Based Rehabilitation

While institutional care for disabled people has been the dominant approach since the 1940s, an alternative approach has developed since April 1984 with the setting up of the first community based rehabilitation programme (CBR) by the Department of Social Welfare at Batu Rakit, Kuala Terengganu with fifty five disabled persons (Rahman, 1995b). Initial guidance and training was provided for by a World Health Organisation (WHO) consultant, Madam Padmini Mendis. As a result of this initial success CBR was introduced in other places both by the Department of Social Welfare and a number of voluntary agencies. This community based approach:

involves measures taken at the community level to use and build on the resources of the community, including the impaired, disabled, and handicapped persons themselves, their families, and their community as a whole (WHO, 1981 : 9).

There is much scope for expansion and it is without doubt that the CBR programmes not only cater for more service users but the approach enhances the potential of disabled people, their families and the community.

The Department of Social Welfare is committed to developing this approach and their target is to set up at least one CBR programme in each and every district in Malaysia by 1995. There are 86 districts in Malaysia. By end of 1995 there are 135 CBR programmes run by the department providing services to 1,770 disabled people at the cost of RM2,123,000 (Rahman, 1995b:12). In 1992 the government began to provide allowances payable to voluntary workers at the rate of RM300 a month for 36 workers. This is considered a boost and a milestone in the development of CBR programmes in this country.

Four CBR training workshops have been held thus far since 1989, bringing together all the key community workers. It has provided opportunities for staff and volunteers to share experiences and network. In a workshop held in 1989 on CBR in Malaysia, the participants using the WHO definition, redefined CBR for application in the Malaysian context. CBR involves the full participation by disabled people, their families and the community in measures taken at the home and community level. Firstly, to reduce the impact of disability and handicap. Secondly, to ensure full acceptance and social integration of disabled people in family and community life. Thirdly, to provide personal support to families of disabled people. Fourthly, to encourage the production of aids and educational materials from locally available resources. Fifthly, to assist disabled people to lead as normal a life as possible, to achieve their full potential and maintain their self-esteem and finally, to prevent disability through counselling, immunisation and family planning.

Even with the introduction of community based rehabilitation, institutional care remains the dominant approach to organised social intervention. However it is important to note that a majority of disabled people to the present day, are home based or rather institutionalised in

their homes. Home care by immediate family members and relatives is the dominant form of assistance available in the informal setting to a majority of disabled people in Malaysian society. Furthermore CBR as currently carried out by the Department of Social Welfare, is reaching out to disabled people who thus far have not received any services rather than a strategy to deinstitutionalise services from the five main government institutions for people with learning difficulties.

4. VOLUNTARY SERVICE ORGANISATIONS FOR DISABLED PEOPLE

The early pioneers were the Christian missionaries who as early as 1911 established a home for the handicapped in general and in 1926 St.Nicholas home specifically for the blind. The Central Welfare Council was established in the same year, 1946 as the Department of Social Welfare, to foster voluntary effort, a balanced approach to welfare pluralism was established in service provision for disabled people. Way back in 1959 the then Minister for Labour and Social Welfare at the Annual General Meeting of the Central Welfare Council said:

I believe that social welfare services flourish best under an arrangement of partnership between government and voluntary bodies ... Voluntary services is important not only in augmenting the government's social services but also as an expression of active and intelligent community life in which each of us understands the opportunities and responsibilities of true citizenship ... Social services can best be performed by voluntary associations working in harmony with the government social services there will always be a place for voluntary effort. (Ong, 1959).

Like the developments with the government Department of Social Welfare, voluntary organisations started with residential forms of care and are now establishing community based programmes with the setting up of CBR programmes. (Jayasooria and Ooi, 1994) The best known are the programmes run by Bethany Home (Telok Intan), Malaysian Association for the Blind (Kuala Trengganu), Malaysian CARE (Rawang) and Program Desa (Sabak Bernam).

In addition to community based services there are three new developments which will gain greater impact in the years to come. Firstly, the establishment in 1992 of the Society for Families of Persons with Learning Difficulties where parents are beginning to play a key role in determining the type of services needed. This is the first parents group which is independent of a charitable organisation in West Malaysia. Since then two others have been established. All other groups are set up within charitable organisations. Parents support groups have the potential for influencing public policies if they are prepared to play an advocacy role. Secondly, attempts to develop not only citizen advocates to work alongside people with learning difficulties but also self-advocacy groups are a positive step forward. This alternate approach is being attempted by certain voluntary organisation like Bethany Home which is situated outside the Klang valley where social clubs have been developed.

These social gatherings provide opportunities for service users to make choices and develop their potential to speak up. This will eventually develop into self-advocacy groups (Jayasooria,1993 : 3).

Thirdly, the development of group homes especially for those in institutional care. The best example of a radical shift was the case of Bethany Home (John,1989,1990) which reorganised its institution in 1982 into a community based service. Long term service users were placed in group homes in the local community for daily living and came to the institution for training or work on a day basis. Following this successful model by a voluntary organisation the Government has been attempting to reorganise its large institutions.

Voluntary organisations depend on the general public to make contributions to fund their activities. The government provides some grants based on number of clients served especially to day care and residential programmes. In 1993 the Ministry for National Unity and Social Development provided grants totalling RM2.2 million to 63 voluntary organisations working

among disabled people throughout Malaysia. (Rahman, 1995) . The Department is also currently providing support to thirteen sheltered workshops run by voluntary organisations through out the country providing job opportunities to 421 disabled people. Only one of these is in the Klang valley.

Coordination of voluntary organisations is currently in a state of confusion. The Central Council for Social Welfare which was established in 1946 to facilitate coordination of voluntary effort has over the years relegated itself to its own direct service projects at a national level and thereby neglecting networking and coordination role. Khoo (1978: 10) notes that the council "exists in name only and is to all intents and purposes defunct". A new coordinating agency, the National Council of Social Welfare Council (NCSW) was established in 1966 to fulfil this task of coordination and networking. Over the years a number of criticisms were raised on the effectiveness of the NCSW. Participants at the 1991 Caring Society Symposium noted that "The NCSW...is selective in its membership and is inaccessible..."(YMCA and CARE, 1993:34). This is because NCSW adopted a restrictive membership policy and have over the years only accepted sixteen organisations as members and therefore not reflective of the total number of voluntary organisations in Malaysia. There are now attempts now to reorganise the NSWC to enable all national based voluntary organisations to be accepted as members as well as adopting a social development agenda (Baginda, 1995). These aspects we will reconsider in Chapter Ten. Organisations working among disabled people could be a member of two coordinating agencies the Malaysian namely the Council for Rehabilitation (MCR) and or the Malaysian Confederation of the Disabled (MCD). We will discuss this aspect in Chapter Six

The nature of voluntary sector involvement among disabled people is the focus of the field study and therefore a comprehensive role of voluntary organisations with regard to the services provided and the challenges faced will be addressed in Chapter Six, Seven, Eight and Nine.

5. SELF-HELP ORGANISATIONS OF DISABLED PEOPLE

The 1960s and the 1970s saw the emergence of the disabled peoples movement which challenged the traditional approaches to welfare provision especially that which isolated them from participation from mainstream society. The first to organise themselves as a group were blind disabled people, who in the 1960s clamoured for the right to have a say in the running of St.Nicholas home. When their attempts failed, they set up the Society of the Blind in Malaysia (SBM) in 1966. Following this trend the 70s and the 80s saw the establishment of other specific disability groups by disabled people themselves, namely the Society of the Orthopaedically Handicapped in 1976, the Society of Chinese Disabled Persons, Malaysia in 1977, the KL Society of the Deaf in 1987, and the most recent is the Malaysian Spinal Injury Association in 1995.

Armstrong (1993) observing the Malaysia context indicated that:

self-help organizations remain a minority among voluntary, non-government organisations working in the disability field but they include some of the more active organisations and their combined contribution is considerable and growing. (Armstrong, 1993:192)

David Korten (1990, 1995), places importance on self-help organisations which he refers to as people's organisations. He identifies them as the fourth sector rather than categorising them with voluntary organisations the third sector as it is popularly done. He notes that there is

neglect in giving importance to people's organisations. We will revisit this theme later in Chapter Ten when we examine more closely the potential of self-help organisations.

A significant development towards the enhancement of the self-help movement was the establishment of the Malaysian Confederation of the Disabled (MCD) in 1985 by SBM, POCAM and SCDPM. Both the KL Society of the Deaf and MASIA are members of MCD. The MCD is a member of Disabled People's International (DPI) and is now the main vehicle for disabled people to express their views and take joint action. They are called upon by the Malaysian government to represent disabled people in policy matters affecting disabled people in Malaysian society.

As discussed earlier, the International Year of Disabled Persons, 1981 and the UN Decade of Disabled Persons (1983 - 1992) have helped to legitimize the concerns of disabled persons in Malaysian society. As a result there are now clear attempts to strike a balance in fostering partnership between disabled people and non-disabled people's organisations in the provision of services. Organisations run by non disabled people dominate service provisions, but there is greater partnership at the level of policy discussion and formulation. This is because disabled people and their organisations are now included and in recent dialogues organised by relevant government agencies have held a prominent position. Furthermore disabled people have become aware of their rights, and they have acquired confidence and credibility as a result of establishing and running their own organisations. They know from experience that they can play a dynamic role in planning and implementing services for the benefit of their fellow disabled people.

Advocacy and policy input has been the major contribution of disabled people since the formation of their organisations. Both at the level of articulating an alternative framework as well as in concrete cases of action, disabled people have made their presence felt in Malaysian society. Godfrey Ooi, rightly acknowledges this when he says that

the disabled have proved that with concerted action they can help to bring about some changes for the improvement of living conditions and for a better quality of life for all disabled people. They have also shown that there is a need for them to work in cooperation with Government authorities and with other non-governmental organisations if they want to bring about positive results. (Ooi, 1994 : 8).

5.1 Voices from the Disabled People's Movement

Disabled people have been coming into the open to express their concerns and views. The social change in the disability movement was spearheaded by visually impaired disabled people. They not only were the ones who first formed an organisation of disabled people namely the SBM but have been clearly analysing the issues and concerns of disabled people in Malaysia.

A number of disabled people in Malaysia have presented papers at various seminars through which they have challenged the dominant charity oriented and segregated approaches in providing services to disabled people in Malaysia. John Kim one of the founder members of the Society of the Blind, ascribes ignorance and negative attitudes by society in relegating disabled people as 'second-class citizens' and 'lesser people'.

I am saying this[says John Kim] because the disabled have been excluded from the general development of the country. From the construction of public roads, buildings and schools, to access to supermarkets, public transport and recreational parks, the special needs of the disabled have not been catered for. This is due to lack of consultation with the disabled to ascertain their views and needs. (Kim, 1991 : 9).

John Kim goes on further to affirm

that a lot of the problems of the disabled can be solved if they are not treated just as helpless clients but as intelligent consumers and meaningfully consulted in the provision of services and facilities just as the general public are. (Kim, 1991 : 10).

Godfrey Ooi has been in the forefront of most of the policy discussions over a decade. He has been one of the key spokespersons of disabled people and participated in all the major dialogues with government officials. He affirms that disabled people are deprived of their rights due to public apathy, discrimination and prejudice. He calls for changes in two areas. Firstly, that there needs to be a change in the approach to providing social services from one based on charity which implies goodwill and low standards to one based on social responsibility and human rights. According to him the help disabled people want is one :

that will enable them to claim their rights as human beings. They do not want the kind of charity that constantly puts them on the receiving end all the time. This means that in planning for the disabled, it is not enough just to give of the heart; 'right mind' and 'right effort' are also required. (Ooi, 1990 :26)

Secondly, from no consultation to providing the mechanism for disabled people to be directly involved in the decision making process. "The exclusion of the disabled can no longer be justified. (Ooi, 1994 : 4).

Anthony Thanasayan (1995a, 1995b) who lost the use of his legs when he was 10 years old and since then has been confined to a wheel chair is an outspoken disability activist. He led a movement of peaceful protest over the reluctance of the management of the Light Rail Transport System to provide the necessary facilities for wheelchair users. His arguments are based on the social model of disability when he argues that:

I feel so trapped. It is not fair to exclude the disabled from the infrastructure. It's not our disability that we cannot overcome but the establishment that has not provided the facilities necessary for us to grow and function normally. (The STAR, 1995).

5.2 Reorganising for effective participation and representation

In order to be effective as one voice disabled people organised themselves. As in the setting up of organisations by disabled people, the visually impaired took the lead when in 1984 the SBM initiated the formation of the National Council of the Blind,(NCBM) which is now the coordinating agency for both organisations 'of' and 'for' serving blind people in Malaysia. Another positive move as indicated earlier was the formation of MCD in 1985. These developments had a positive effect on disabled people and the policy makers because they could now be identified as a co ordinated group which facilitated their role in policy input.

Four key examples could be cited of disabled people and voluntary organisations playing a direct role in advocacy and policy input. Firstly, the role played by MCD in making representation on behalf of disabled people. For example the MCD submitted to the government a Memorandum on access to public facilities (July 21, 1988). This has resulted in the proposed amendments to the Uniform Building By-Laws (1984). More recently the MCD were involved in closed door dialogues on access for disabled people on the new project of the STAR light Rail Transit System in the capital city. Secondly, the participation of voluntary organisations at the national prebudget dialogue since 1991 where a disabled person represented the concerns of disabled people and their organisations (Ooi, 1992).

Thirdly, a series of workshops and conferences⁴ was organised by voluntary organisations where key policy recommendations were formulated and submitted to relevant government bodies. Fourthly, disabled people and their organisations were represented in the Special committee set up by the Ministry of National Unity and Social Development in preparing a Cabinet report on disabled people which was presented to the Cabinet in December 1992. Of the twelve representatives from voluntary organisations, five of them were disabled people representing MCR and related organisations.

These opportunities affirm the possibility of grass-root movements discussing major issues affecting disabled people in Malaysian society and channelling those recommendation to relevant government agencies for consideration. These are encouraging indicators, as participation in policy formulation and implementation are an integral part of citizen rights and responsibilities. Since IYDP disabled people are coming to the forefront to exercise this right within the political process. However the major draw back is that self-help groups and voluntary organisations are not devoting funds and resources to prepare well researched documents to make their case clearer during policy discussions. This is the next stage of development which is needed to strengthen advocacy attempts.

⁴ Three main gatherings were initiated by Malaysian CARE together with a number of voluntary organisations including organisations 'of' disabled people. The researcher was actively involved in the coordination of these together with a number of disabled people namely Godfrey Ooi and Bathmavathai Krishan. The three gathering are: Firstly, The Equal Opportunity workshop (May 20, 1989) which produced two documents *Equal Opportunities for the Disabled*, Memorandum to the National Economic Consultative Council, (August 1989) and *Justice, not Charity*, (Spastic Centre, 1989). Secondly, Workshop on Disability Issues (August 23-25, 1990) which produced a report entitled *Disabled Persons, Clients or Consumers?* (Malaysian CARE, 1992). Thirdly, The Caring society workshops and the National Symposium organised by Malaysian CARE and the YMCA (April to Oct. 1991). A report entitled *Fostering a Caring Society, Issues and Challenges from an NGO Perspective*, (Malaysian CARE, July 1993) was released. The findings from these different programmes were released to relevant authorities. Disabled people have played a key part in all these gatherings.

5.3 Difficult realities for exercising political participation in Malaysian Society

In the Malaysian context disabled people are faced with three hard realities which they will have to overcome. Firstly, the issue of linking micro and macro concerns. Voluntary organisations including self help groups are often focused on micro concerns. Policy matters require work in social and political analysis, accurate research and documentation which are often outside the scope of most organisations. They lack the resources and the personnel to effectively carry it out. The attempts cited earlier are ad hoc attempts where individuals from the various organisations have, for a limited period, devoted attention to a national policy issue. However this is often not their major task within the organisation. Therefore effective monitoring is lacking as well. Michael Edwards and David Hulme correctly observe

the failure of NGOs to make the right linkage between their work at the micro-level and the wider systems and structures of which they form a small part. (Edwards and Hulme, 1992 : 13).

It is therefore necessary for organisations like MCD to be well staffed to do the necessary background research in order to be effective in the policy arena.

Secondly, Malaysians due to the political climate have in the majority withdrawn from public protest, action and public litigation. This analysis is clearly described by Esther Lim who writes that :

the litigation consciousness among the Malaysian disabled is practically absent and they are mostly in the dark about their rights. (Lim, 1993 :23).

The popular approaches in the West towards creating public awareness are public protest and court action. This inner spirit of fighting for ones rights is silenced by cultural, social and political factors in Malaysia. According to Esther Lim (1993) the way out is increasing the

confidence and assertiveness of disabled people. One will have to do more than this, but it is the first step forward. If not fatalism will prevail.

While Esther Lim (1993) is right to draw the cultural differences between the West and Malaysia, it is also essential to understand the democratic space within which Malaysians operate. Due to experiences in the past there is a climate of fear⁵. Lee (1987), notes the threats against human rights especially with regard to citizens' participation from within the Federal Constitution which allows Parliament to enact legislation in the name of security and public order. Fundamental liberties like freedom of speech, assembly and association are restricted. A law that puts fear in the hearts and minds of Malaysians is the Internal Security Act, 1960 which provides for preventive detention without trial. Muzaffar (1986) observes that it is undeniable that there have been numerous misuses of this legislation by the Executive in power.

Thirdly the major hurdle is the approach one undertakes within the Malaysian political climate. Too critical and confrontational an approach is not welcomed in Malaysian society especially by the ruling politicians. Therefore the approach taken both by disabled people and some voluntary agencies is to work within the structure in making recommendations or changes. The prevalent approach is one of persuasion and friendly 'chit chat' over tea or a meal rather than one asserted on the basis of rights and entitlements. But what is one to do when dialogues do not materialise into positive action. This is the case with the closed door

⁵ The fear centres around the use and abuse of the Internal Security Act(1960). As Muzaffar notes it hangs like a 'sword of Damocles' and "discourages the emergence of a more courageous and committed citizenry" (Muzaffar,1986:297). In October 1987 more than 100 people were arrested under the ISA and of these 35 individuals were served two years detention orders. Of these a third were individuals involved in NGOs. (Tan and Singh, 1994:25)

dialogues with the relevant Ministries on the issue of access for disabled people on the newly constructed Light Rail Transit System. Although the issues were well published in the media, the authorities have not taken the appropriate action to make provisions such as lifts in order for wheelchair-users to use this major new public transport system being developed in the capital. MCD (Tang, 1995) has called for government intervention in order to bring positive results.

A number of disabled people took the opportunity to organise a press conference in support of the Malaysian Prime Minister's statement that:

Malaysia was fully committed to helping the disabled and the country could be the region's model of excellence for the less fortunate. (Saithuruka, 1996:10)

About fifty disabled people came together for this press conference organised by the Light Rail Transit Action Group set up by disabled people. They took this opportunity not only to support the PM and in so doing use the occasion to highlight the concerns of disabled people. The media provided good coverage of this gathering. The *pro tem* Chairperson of the action group, Christine Lee said during the press conference:

Public transport and facilities provided in buildings should be more disabled friendly. The services are inadequate compared with other countries. Buses don't cater for us and even the LRT which will be launched...does not have facilities for us. (Saithuruka, 1996:10).

Anthony Thanasayan who was one of the speakers at the press conference on reflection of their gathering had this to say:

As the flashes from the photographers gleamed across the crowded living room, I was suddenly overwhelmed and all choked up to see my friends who had struggled diligently for our cause coming out boldly and unashamedly to speak about our plight. Indeed, while there has been very little change in attitudes and accessibility for us in our society, over the years, we can be thankful for one positive fact- in our difficulties, there has been much personal growth for us all. (Thanasayan, 1996:14)

What is clearly emerging in Malaysian society is the political consciousness of disabled people and they are exploring different possibilities. However the wider political climate for pressure group politics reveals the realities. In this context Lim Teck Ghee (1995) rightly observes:

When issues such as welfare policies or youth and child development are taken up, the government is usually appreciative of input from the NGOs and an exchange of information takes place to facilitate the relevant projects... Tension arise, however, when some NGOs actively seek to make the political system more accountable to public interests or to make the development process more transparent and people oriented. (Lim, 1995:167)

A clear example of State reaction to the political advocacy role of disabled people is the case of the SBM during the proposed amendments to the Societies Act in 1981. This illustration is recorded by Gurmit Singh (1984). In Malaysia the freedom of association is regulated by the Societies Act 1966. In 1981 there was a move by the government to create a new category called political societies.

A political society is defined as a society that seeks to influence **in any manner** (researcher's emphasis) the policies or activities or the functioning, management, or operation, of the Government of Malaysia, or of any department or agency of any such Government or Authority. (Singh, 1984 : 83).

The SBM was one of the first organisations along with eighteen others who objected to this move by the government. The SBM was part of the Societies Act co-ordinating committee which was set up by 64 societies that launched a national campaign on Freedom and Society between August 29 - 31, 1981. The Registrar of Societies acted first against SBM stating in a letter that due to the nature of its objectives and activities it will be designated a political society. This pressure was sufficient to enable the withdrawal of SBM from the protest activities. In due time the government made changes to its proposed amendments and the clause defining societies as political was eventually dropped. However the impact both on SBM and other welfare based voluntary organisations was to persuade them to toe the line of the government. SBM today is a service based agency and any advocacy it does, it works

through MCD. It is without doubt that disabled people have now relegated themselves to discuss only issues directly affecting them rather than working alongside others on issues of national concern.

Goh Ban Lee (1991) is right in his general assessment of Malaysian society that independence has only conferred a certain degree of power on the citizens. On the whole :

the power has been largely limited to casting votes to decide whom they want to be their leaders or which party they want to form the next government. The public has generally been denied opportunity to influence governmental decisions. Even the choice of local councillors has been taken away by the abolition of the local government elections. (Goh, 1991 : 115).

However it is within this political climate that certain creative attempts to influence public policy working from 'within' and to be seen by the government as 'insiders' will hopefully bring the needed change to equalise opportunities for disabled persons in Malaysian society.

6. Chapter Conclusion

This chapter provides a comprehensive overview of the services organised for, with and by disabled people in Malaysian society with specific reference to the State policies and services along with the emergence of a disabled people's movement. It provides a useful background for the in-depth study of voluntary organisations in the Klang valley and their role in enabling and empowering disabled people to gain membership within Malaysian society. While attempts are being made by the Malaysian government to address the needs and issues of disabled people we have noted that what is being done is insufficient. They can be categorised as predominately residual in nature with a heavy reliance upon the voluntary and informal sector. What was also noted is that the current services are not comprehensive and a majority

of disabled people unlike other Malaysian citizens are not yet benefiting from the economic development taking place.

MacPherson's (1992) analysis of the newly industrializing countries in Asia is significant. He notes that while the Asian Pacific Ministers endorsed the social development agenda nonetheless the dominant approach was one of 'band aid', 'reactive', 'sporadic' and 'piecemeal'. While Malaysia has made much progress and has demonstrated with great success general poverty eradication programmes, especially among rural Malays (Malaysia, 1995), MacPherson's description accurately reflects the reactive, piecemeal attempts to address disability related issues in Malaysia.

All around the developing world according to Coleridge (1993) disabled people and their organisations are playing an active role through self-advocacy. This is clearly indicative of the role played by key Malaysian activists and the MCD. The delicate political and cultural context determines strategies appropriate for social change. Disabled people are beginning to tap into the opportunities available.

While Malaysian disabled people affirm citizenship rights and call for inclusion into Malaysian society their experience in a newly industrialising country is not the same as that described by Barnes (1991) in the British experience. Barnes highlights that in the British experience while cultural considerations had relevance, it was industrialisation which alienated them from mainstream society. He said it was largely due to

the economic and social upheavals which accompanied industrial development... [which] precipitated discrimination becoming institutionalised throughout society' (Barnes, 1991 : 26-27).

However, this is not the case for Malaysia, a newly industrialising country in Asia. Malaysia is currently undergoing rapid industrialisation and disability issues have surfaced due to the social and economic progress taking place. Society is taking account of the concerns raised by disabled people through appropriate action however inadequate. Furthermore due to the global awareness on disability issues and its impact, positive changes are taking place. It is too early to determine the policy outcome in Malaysia but there are positive indicators to ensure that disabled people will not be sidelined in the year 2020. In many ways, economic growth provides a window of opportunity for disabled people. Malaysian disabled people are seeking a share of the economic cake and their role in recent years is beginning to set the agenda for their inclusion and share in Malaysian society.

METHODOLOGY

1. Chapter Introduction

This chapter is concerned with the methodology of the inquiry into social work practice among disabled people in general as well as from a citizenship perspective in the Malaysian context. Chapters Two, Three and Four contain critical analyses of the literature on citizenship, disability theories and Malaysian policy and provision for disabled people. The analysis of Malaysian provisions for disabled people in Chapter Four is based on primary as well as secondary sources.

This study is an original piece of empirical research. The search of primary and secondary Malaysian documents indicates that there has been no other systematic study of voluntary organisations working among disabled people in the Klang valley of Malaysia. This situation is similar to that of Drake (1992 : 123) who in his study in Wales also discovered that there was very little documentation and research done on voluntary organisations. The fieldwork reported in Chapter Six provides a comprehensive analysis of voluntary action among disabled people in the Klang valley. Furthermore the typology of voluntary organisations which emerges from analysis of the field study has relevance to other disadvantaged groups in Malaysia, and possibly other newly industrialising countries. What is more the brief history of the disabled people's movement in Malaysia together with the account of their perspectives as citizens is the first of its kind. In many ways the field study through the presentation of papers during the course of the investigation, some in collaboration with two disabled activists, has pioneered a new approach to research, analysis and publication on disability and Malaysian society.

Before discussing field study methodology and providing a detailed account of the strategies adopted, it is important to review disabled people's criticisms of how non-disabled researchers have conducted research on disability. This discussion is important and consistent with the citizenship model of social work practice which involves working alongside and with disabled people rather than for them. The reason why collaborative, participatory and action research methods were adopted are discussed together with a rationale for the integration of quantitative and qualitative methods.

Barnes (1990) started his methodology section with an autobiographical account, stating clearly his main reasons for interest in disability. The researcher acknowledges himself as one who has no direct experience of impairments, except that he wears spectacles, and therefore a non disabled person, but like Driedger (1989) this researcher regards himself as 'an ally' of the disability movement in Malaysia. The researcher believes this is consistent with Morris's (1992 : 164) reference to non disabled researchers as 'allies'. The researcher's introduction to social work with disabled people began with his role in Malaysian CARE from 1986, as Malaysian CARE runs residential and day care programmes for disabled people. However direct contact since 1989 with Godfrey Ooi and Bathmavathai Krishan, two disabled people who are leaders of the Malaysian disability movement, has influenced him most profoundly. Opportunity to work together closely came when they were members of the organising committee of the 1989 workshop on equal opportunities for disabled people in Malaysian society and drafting the memorandum that was submitted to the government (Memorandum, 1989). Together they edited the document and since then have become close friends together with their families. Long hours spent with them has radically challenged the researchers perspectives as a senior executive of one

of the largest charities in Malaysia. The researcher contributed management expertise, research and writing skills and they contributed their experience, intellectual expertise and grass roots contact with disabled people to develop a collaborative approach to documenting, analysing and advocating social change in the Malaysian context. Together they have presented a number of policy papers at leading conferences in Malaysia and published a number of them (Krishan *et.al.*, 1989; Jayasooria *et.al.*, 1992; Jayasooria and Ooi, 1994; Jayasooria *et.al.*, 1996). The approach adopted is not that of a 'safari social scientist' (Bulmer and Warwick, 1983) who makes a brief field trip and then disappears after the data is collected. An alternate approach consistent with collaborative research has been developed as the researcher has been working alongside disabled people and voluntary organisations between 1989 and 1995.

The researcher is conscious that he is a non disabled person but over the years have developed friendship with disabled people and their organisations. He acknowledges that disabled people must take the lead but also that non disabled people can be 'allies', 'friends' and 'partners' working alongside disabled people and accountable with a social model of disability. Networking with disabled people and their organisations since 1989 has enriched the researcher's understanding of the disability issues and concerns in Malaysia. The researcher believes that his experience in voluntary sector management and contact with the majority of voluntary organisations run by non-disabled people for disabled people has facilitated a dynamic interaction between the two groups and is challenging the inappropriate models which currently dominate voluntary sector services in the Klang valley of Malaysia.

2. RESEARCH AND METHODOLOGICAL ISSUES

Disabled people have challenged the methodological assumptions and strategies adopted by non-disabled social researchers. They have expressed their disenchantment with much of the research done on disabled people and argued that it has contributed to their oppression. (Oliver, 1992, 1993a, 1996; Barnes, 1992, 1996a; Morris, 1992; French, 1994).

Barton (1992: 99) provides a helpful, four fold summary of disabled people's criticisms. Firstly, there is the misunderstanding about the nature of disability. Secondly, the experience of disability has been distorted. Thirdly, there is the failure to involve disabled people and finally, the research done has not resulted in improving the quality of the life of disabled people.

Among disabled people the most notable critic of social research is Michael Oliver (1992, 1993a, 1996). Applying John Rowan's (1981: 93) work on alienation in which research subjects are being used for someone else's ends, Oliver (1992 : 103) points out how disabled people are in a similar way alienated from the process of research.

Developing this thought, Zarb (1992 :137) draws the difference between *researchers who* simply consult disabled people and those who are accountable to disabled people and affirms that being accountable is compatible with the 'principle of genuine participatory research'. The issue of who controls research is at the heart of disabled people's criticism of contemporary social research on disabled people conducted by non-disabled researchers. Oliver goes on further to show how disability research is captive to "the methodological individualism inherent in positivist social research" (1992 : 107). Both Oliver (1992) and

Abberley (1992) link this approach to research with the individual model of disability, which sees the problems that disabled people face as being caused by their individual impairments rather than analysing how society disables impaired people.

At a conference on Researching Physical Disability (1992), it was noted that:

disabled people told non-disabled researchers that they had no right to be researching the disability experience. (Shakespeare, 1993 : 255).

What emerged from the discussion and subsequent writing was not that non-disabled people have no role but their role was now being defined by disabled people. Barnes approach is the most positive towards non-disabled peoples role as he says that he is

not convinced that it is necessary to have an impairment to produce good quality research... (Barnes, 1992 : 121).

He goes on to highlight other social indicators apart from impairment like class, education and employment that could be the cause of the cultural gulf. However Barnes sympathetic position is from within the emancipatory model of social research. Oliver (1996 :168) also does not say that those who have no direct experience of impairment have no contribution to make to the disability movement. He does, however, warn that disabled people will construct their own research enterprise without them, if the researchers fail to recognise the need to work together. (Oliver, 1993a)

Both Oliver (1992) and Morris (1992) call non-disabled researchers to focus not on disabled people but the able-bodied society and non-disabled people's behaviour towards disabled people. In this context Oliver (1993a) acknowledges that currently disabled people do not yet have the knowledge or skills to carry out appropriate research and that

researchers do not have the appropriate experience. Therefore there is a need for a partnership between the two to facilitate it. This partnership according to Oliver (1993a) should be in all stages of the research so that planning, design, fieldwork, analysis and report writing should all be jointly constructed by researchers and disabled people.

Oliver (1992) calls for a paradigm shift from the current research approaches towards emancipatory research. In this approach he says that:

researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose. The task for emancipatory research is not, as is sometimes implied, to help the researched to understand themselves better, but to develop its own understanding of the lived experiences of these very subjects. This is, of course, a dialectical process in which research can play a significant part. (Oliver, 1992 : 111).

Colin Barnes explains that:

emancipatory research is about the systematic demystification of the structures and processes which create disability, and the establishment of a workable 'dialogue' between the research community and disabled people in order to facilitate the latter's empowerment. (1992 :112).

Shakespeare (1996:118) has major reservations with emancipatory research and is

cynical about the possibility of research achieving major changes... Ideas clearly have a role, but actions decide the day. (Shakespeare, 1996:18).

While noting Shakespeare's caution it is important to note that emancipatory model of research advocated by Oliver and Barnes is similar to participatory action research and critical issues in the research process has been raised by others as discussed in the rest of this section. What is new is the application of the principles to disability research and building upon an existing research tradition of collaborative inquiry.

Participatory action research as Peter Reason (1988, 1994) explains is a research with and for people rather than on people. He goes on further to call it a 'co-operative inquiry' which

is a way of doing research in which all those involved contribute both to the creative thinking that goes into the enterprise-deciding on what is to be looked at, the methods of the inquiry, and making sense of what is found out- and also contribute to the action which is the subject of the research. (Reason, 1988 : 1).

The above discussion of the negative aspects of the positivist *assumptions and methodology* in social research as criticised by disabled people, has been critically reviewed by other social researchers (Silverman, 1985; Reason, 1988, 1994; Whyte, 1984, 1991; Hammersley, 1993; Hart and Bond, 1995). A number of these concerns are discussed here.

Peter Reason (1988, 1994) describes a participatory or co operative process of doing research which is a research 'with people' rather than 'on people'. He explains that

it is about inquiry as a means by which people engage together to explore some significant aspects of their lives, to understand it better and to transform their action so as to meet their purposes more fully. (Reason, 1994 : 1).

Reason explains that this process is not just to incorporate some participatory methodology into a positivist world view as 'a participatory methodology needs to rest on a participatory worldview" (Reason, 1994 : 1). He goes on to explain two key aspects of participatory action research (PAR) which has developed from within the tradition of liberationist movements and the influence of Paulo Freire (1972). The first is to produce knowledge and action directly useful to the community. The second is consciousness raising or conscientization (Reason, 1994 : 48). Reason further notes that it is easier to describe the ideology of PAR rather than its methodology. This is because according to Reason

it aims to develop an alternative system of knowledge production based on the people's role of setting the agendas, participating in data gathering and analysis, and controlling the use of outcomes. In addition, PAR places emphasis on the emergent processes of collaboration and dialogue which empower, motivate, increase the self-esteem and develop community solidarity. (Reason, 1994 : 48).

Whyte likewise indicates that it is a research process where:

some of the people in the organisation or community under study participate actively with the professional researcher throughout the research process from the initial design to the final presentation of results and discussions of their action implications. (Whyte, 1991 : 20).

Action research was first pioneered by Kurt Lewin (1951). Stephen Kemmis and Robin McTaggart (1992) describe Lewin's research process as a spiral of steps namely, to plan, act, observe and reflect.

Lewin's deliberate overlapping of action and reflection was designed to allow changes in plans for action as the people involved learned from their own experience. Put simply, action research is the way groups of people can organise the conditions under which they can learn from their own experience, and make this experience accessible to others. (Kemmis and Mc Taggart, 1992:7)

Hart and Bond (1995) state that Lewin used the term action research:

as a way of generating knowledge about a social system while at the same time, attempting to change it. (Hart and Bond, 1995 : 13).

Over time it has become a popular approach in education, community development, management research and nursing. According to Reason:

action research is concerned with the transformation of organisations and communities towards greater effectiveness and greater justice. (Reason, 1994 : 49).

With such a strong emphasis on qualitative methodology thus far in the discussion, it is important to ask whether there is any use of quantitative approaches within the participatory process. Whyte (1984), Warwick (1983), (Whyte and Alberti, 1983), Silverman (1985) and

Hakim (1987) make a case for an integration of methods. Whyte, highlights how the "reliance upon a single research method is bound to impede the progress of science. (1994 : 149). Silverman (1985) indicates that quantitative methods can be useful and calls for a balanced use of qualitative and quantitative methods. Silverman (1985 : 17) goes on to highlight the potential value of simple counting procedures which can support the researchers interpretation as well as give a picture of the whole sample in summary form. Hakim likewise notes the complementary nature of the qualitative and quantitative approaches, noting that qualitative approaches extend the survey results and that the quantitative findings place qualitative findings within the statistical context. Reason (1994 : 48) too acknowledges that PAR is characterised by 'diverse methods'.

One final issue which has come to the surface of disability research (Barnes, 1996a; Shakespeare, 1996; Bury, 1996) is the concept of independent research and researcher. Barnes (1996a) critically notes the reality that disability research is currently caught within a university system where research is being done for academia and influenced by funders on how and on what to research. This situation is further complicated by the growing commercialisation of social research. There is therefore no 'mythical independence' according to Barnes. He goes on further to state that

disability research is about researching oppression...[Researchers should be joining disabled people] in their struggles to confront and overcome this oppression. Researchers should be espousing commitment not value freedom, engagement not objectivity, and solidarity not independence. There is no independence haven or middle ground when researching oppression: academics and researchers can only be with the oppressors or with the oppressed. (Barnes, 1996a:110)

Mike Bury (1996) in response makes a defence of independent research and does not subscribe to the view that "a particular section of the disability movement should control

the research agenda" (Bury, 1996:113). His appeal is for good research done by 'disabled' or 'able bodied'. His final appeal is that :

disabled people and social researchers should work collaboratively together, where possible, to influence the research agenda in a positive and pluralistic direction, to tackle the range of issues involved in disability. (Bury, 1996:113)

Shakespeare (1996) in responding to Barnes makes a distinction between accountability to one's research subjects and accountability to the disability movement; between commitment and accountability to the movement and finally between the role of an academic and that of an activist. His view is that "sociologists must have the space and the integrity to tell it how it is" (Shakespeare, 1996:119).

This study acknowledges the criticisms made by disabled people and therefore adopts the methodology of participatory action research which is believed to be consistent with the citizenship model of social work. Both qualitative (participant observation, in depth interviews, feed back sessions) and quantitative (postal questionnaires) research methods were used and integrated.

3. RESEARCH QUESTIONS

In this study on citizenship, social work and disabled people in Malaysia the attempt is to develop and determine the value and applicability of a citizenship model of social work practice among disabled people in Malaysia. From the literature search as written in Chapter Two and Three a citizenship model of social work practice has been formulated in the concluding section of Chapter Three. The focus of the field study among voluntary organisations working among disabled people was to determine its value and applicability. In the light of Chapter Four on Malaysian society and the field study findings as written

in Chapter Six, Seven, Eight and Nine, the citizenship model is critically reviewed and reformulated in Chapter Ten.

As we noted in Chapter One the central research question concerns the relevance of the current discussion on citizenship on social work practice among disabled people with specific reference to voluntary organisations in the Klang valley region of Malaysia. In formulating a citizenship model for social involvement among disabled people in Malaysia, the following subsidiary research questions were helpful. These questions were the focus of the literature search as well as the field study. The questions are divided into three main areas namely citizenship and Malaysian society, disabled people and Malaysian society and finally disabled people and voluntary organisations. These became the base upon which more specific questions were developed for the organisational postal questionnaire (Appendix 2), organisational semi structured interviews (Appendix 3), service users' case study outline (Appendix 4), and social work practice questionnaire (Appendix 5).

Citizenship and Malaysian Society

To what extent is the concept of citizenship relevant to Malaysian society and readily understood by Malaysians? Is there any historical relevance and practical application to Malaysian society in general ?

Is there a tension in Malaysian society between individual and collective approaches in providing equal opportunities for all Malaysians?

Disabled People and Malaysia Society

What is the position of disabled people in Malaysia, are they citizens of the nation with equal rights and responsibilities or just objects of charity ?

How do disabled people in Malaysia make a claim for their rights and what are the factors which they identify that hinder their achievement of full membership in Malaysian society?

What role have organisations run by disabled people played in challenging inappropriate approaches to practice and what action have they taken in enhancing the rights of disabled people in Malaysian society ?

Disabled People and Voluntary Organisations

What are the models and approaches which dominate social work practice in the voluntary sector in the Klang valley? How do voluntary organisations organise their services for disabled people? Is it 'with' disabled people, or 'for' disabled people ?

To what extent is the citizenship model of social involvement compatible with the situation in Malaysia as a model for social work practice ? What are the implications of this practice which aims to facilitate self-reliance, independence and empowerment of disabled people and their movement ?

In cooperation with disabled people what changes can be introduced to voluntary sector practice so that it provides for greater involvement of disabled people and their movements?

4. FIELD RESEARCH STRATEGIES

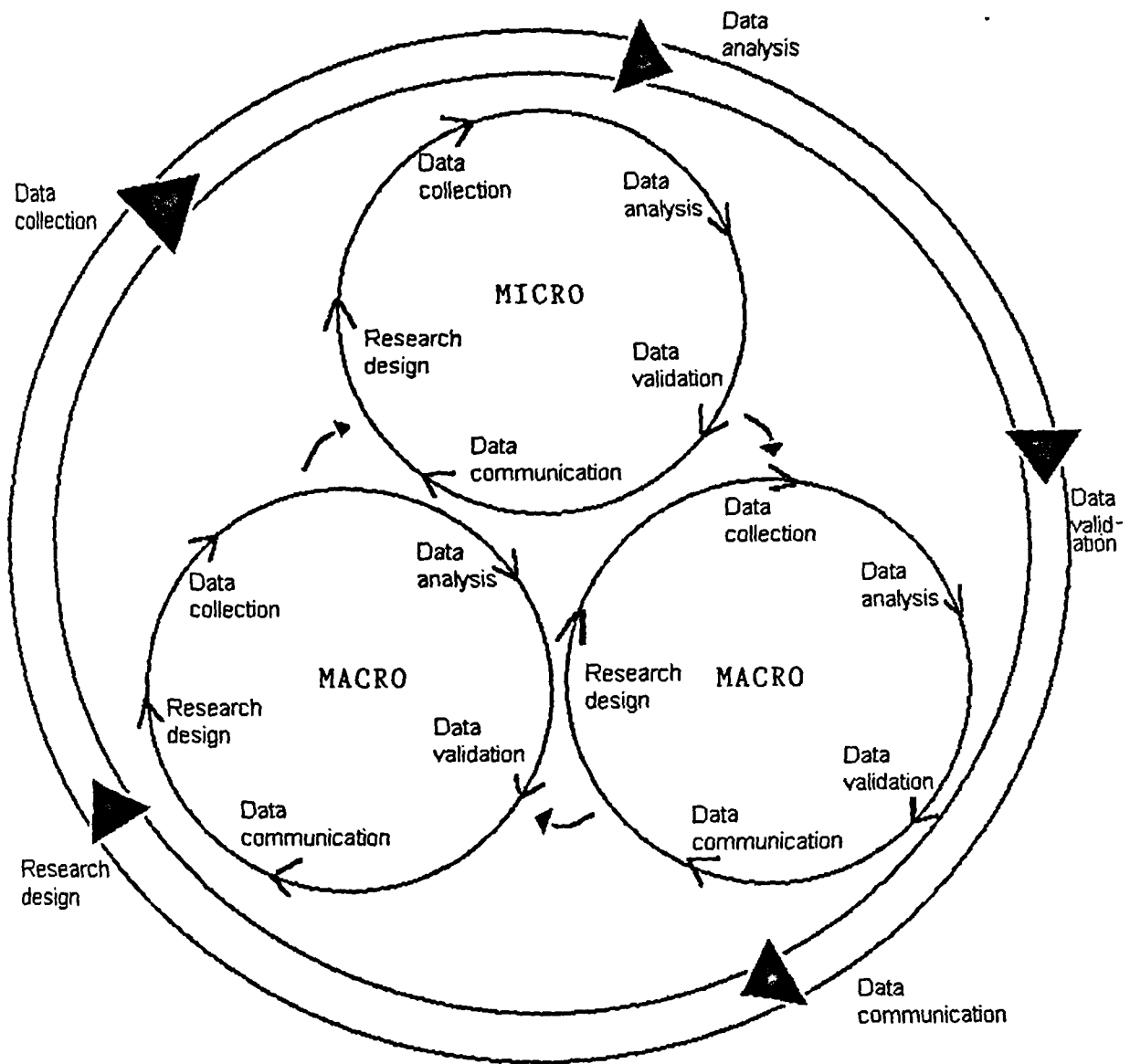
The field study was carried out in three phases. Table 2 on research strategy illustrates this process. There is a movement from firstly providing a macro perspective of the voluntary organisations providing services for or with disabled people in the Klang valley of Malaysia. As indicated earlier this was a necessary first step as there was no comprehensive documentation of the services provided. On completing this aspect the next stage was to do an indepth study of two models of welfare provision out of the four which emerged as a result of the first phase study. The final stage was returning to a macro perspective in gathering feedback on the relevance of the citizenship model of social work practice for Malaysia. Hakim (1987 : 28) sees the value of both a macro perspective which offers a 'bird's eye view' and micro perspective, a 'worm's eye view'. The rationale for the third phase in drawing feedback is to ensure that the findings would have a wider application. In this context Warwick (1983 : 284) notes that one of the advantages of combining research methods is the possibility of generalizing the findings. Therefore, in doing this three-fold approach this research has attempted to link and integrate macro and micro, quantitative and qualitative, policy and theory.

Figure 2 on collaborative action research cycle illustrates the research process in a cycle of research design, data collection, data analysis, data validation and data communication. Within the big outer cycle are three smaller cycles going through the same process. The researcher has attempted to involve disabled people through this research process. Details of the collaborative attempts is listed out in subsequent sections in this chapter.

Table 2: RESEARCH STRATEGY (MACRO-MICRO-MACRO) PROCESS

	MACRO	MICRO	MACRO
Focus	Comprehensive study of voluntary organisations in the Klang valley and models of social work practice.	Indepth study of two voluntary organisations from two different models (charity model and self-help model)	Feedback on the Citizen's model for social involvement developed in Chapter Three.
Duration	Oct.93 - April 94	Aug. 94 - April 95	Jan.95 - April 95
Methods	<p>Postal organisational questionnaire (31 org.)</p> <p>Field visits (10 org.)</p> <p>Interviews (19 people)</p> <p>Workshops April 9, and 16, 1994</p>	<p>Participant observation (Aug.- Dec 94 at 2 org.)</p> <p>Organisational study</p> <p>Interviews - service users (28 disabled people)</p> <p>Feedback meetings with users March 31,95 and April 2, 1995</p>	<p>Citizenship model Feedback interviews & Social Work practice questionnaire (14 people)</p> <p>Workshop on citizenship model March 11,1995</p>
Other Collaborative action	<p>Researcher and disabled people between Feb. 1989 to Dec. 1995</p> <p>Participation and presentation of papers in National social policy seminars/workshops. Joint publication of booklets and articles locally and internationally.</p>		

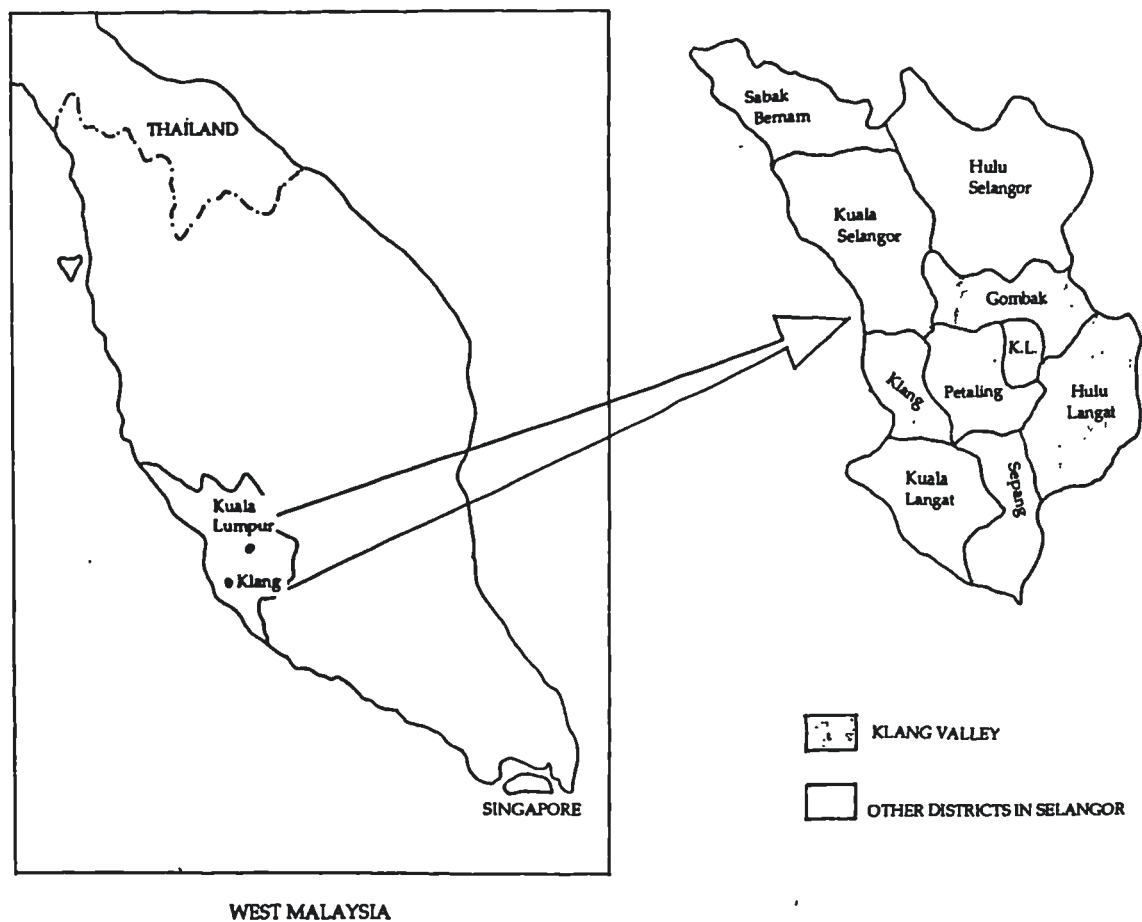
Figure 2 COLLABORATIVE ACTION RESEARCH CYCLE



4.1 Context of the Field Study

The field study was carried out in the Klang Valley which is currently the fastest growing region in Malaysia. 18% of the nation's population live in this region which covers a total land area of approximately 423.6 square kilometres. The Klang Valley region comprises Kuala Lumpur (the Federal capital) and the districts of Petaling, Klang, Gombak and Hulu Langat in the state of Selangor. (See figure 3)

Figure 3 : Map of the Klang Valley Region



4.2 Duration of the Field Study

As illustrated in Table 1, Phase one (macro) of the field study was carried out between October 1993 and April 1994 and included the research design, consultation with disabled people, questionnaire circulation and tabulation, field visits and interviews as well as a discussion group. Phase two (micro) of the field study, the participant observation was carried out between August 1994 and December 1995. However there was continuing direct involvement between January and April 1995, and in depth interviews and discussion groups were also carried on during this period. Phase three (macro) was also carried out between Jan. and April 1995.

4.3 Researchers' role

Because of previous work experience with voluntary organisations in the Klang valley from June 1986 the researcher had easy access to the agencies. A majority had some contact with the researcher and this provided a useful introduction. Furthermore the researcher was also well acquainted with a number of disabled people through collaboration with them previously mentioned. Before the start of the field research, the researcher hosted a focus group which was held on October 24, 1993 and attended by nine people - four disabled people, two parents and three non-disabled people. The discussion lasted for about two hours. They represented nine different voluntary organisations. The researcher introduced the field study and asked for their comments and feedback. Overall there was positive interest and support for the project. The main reason for this was the intention to involve disabled people and others from the voluntary organisations in the research process. This discussion proved useful as the proposed research received the support of both the disabled people and others from the voluntary organisations.

In phase two of the field study the researcher offered himself as a volunteer, in his professional capacity as a resource person in providing consultancy, research and training. The researcher was a participant observer, providing an appraisal of the organisations with regard to policies, services and structure. Two possible difficulties can be noted in this context. The first is similar to what Drake (1992) describes as familiarity with the subject matter. There was the danger of overlooking important aspects as a result of being familiar with a voluntary sector agency and this was something the researcher had to be conscious about in order to be truly reflective. The second was the danger of being regarded as an expert in the field due to the senior management position the researcher held in Malaysian CARE till the end of 1993. Once again the researcher had to ensure that he developed close rapport with the people. However by the time phase two of the field study began there was a change in my job and so the status position was less of a hurdle.

One of the objectives of the field study within the action research tradition was to influence organisational changes towards the greater involvement of disabled people. The researcher in the micro phase played a part alongside disabled people, in initiating and facilitating analysis of the services provided. Hart and Bond (1995) recommend the researcher:

to act as a catalyst to help members define a problem or think differently about an existing one, and interventions may be made by the researcher which offer the organisation a new way to think about an old problem. (Hart and Bond, 1995 : 22).

This could be compared with the researcher's role in the field study. This aspect of influencing organisational changes together with disabled people is described more fully later.

It is further important to note that from February 1989 the researcher was working alongside disabled people in social policy discussions at seminars and conferences. At many of these programmes papers were presented and several of them were published. Throughout the period from February 1989 to December 1995 this partnership matured to become a team network with some of the leading people in the disability movement in Malaysia.

5. PHASE ONE OF THE FIELD RESEARCH (MACRO)

5.1 Specific Research Focus

Phase one of the field study was conducted on voluntary organisations providing services to disabled people in the Klang valley. A provisional directory (CARE, 1993) served as the basis of an exploratory study. The 1993 directory listed twenty seven voluntary organisations in the Klang valley working among disabled people. The field study extended this by another four organisations and therefore all 31 voluntary organisations (see Appendix 1), which provide direct services to disabled people based in the Klang Valley was the focus of the study. This includes both 'organisations for' and 'organisations of' disabled people. The field study attempted to provide a comprehensive overview of all these organisations. The data and analysis of this section of the field study is presented in Chapter Six. In accordance with the rationale described in the previous section a variety of methods was used in gathering data.

5.2 Quantitative data collection

A documentary analysis was conducted on all the 31 voluntary organisations by firstly, circulating and tabulating a postal questionnaire (see Appendix 2), secondly, gathering and

analysing published materials (eg. mission statement, annual report). The objective of this exercise was firstly, to make a general assessment of the type of services provided and the ethos that undergirds it, secondly, to determine the extensiveness of the services ie. the number of persons catered for, by what number of staff and at what cost.

The questionnaire was posted to each organisation early in December 1993. Personal telephone calls were made in January 1994 with the assistance of volunteers, and all 31 organisations returned the questionnaire by early March. A majority enclosed reports and other relevant information.

5.3 Qualitative Data Collection

Field Visits

In order to further verify the data gathered through the postal questionnaire, the researcher made half day field visits to 10 of the organisations. Permission was sought through a telephone conversation. Five of these were 'organisations of' disabled people and the other five were 'organisations for'. During these visits the researcher had the opportunity to see the facilities and interact with those involved in the services. Of these two were eventually selected for the second phase in-depth study. The criteria used are described later in this chapter.

Semi Structured Interviews

A semi-structured questionnaire (See Appendix 3), was used. Nineteen people were interviewed. To preserve anonymity of the interviewees the names are pseudonyms. However other relevant information is provided. See Appendix 6. Of the nineteen, nine are

disabled people. The interviewees are identified by their role in the organisation (elected officials, executive staff and service staff).

Sixteen of the interviews were taped and transcribed with the assistance of a disabled person. The other three interviewed were uncomfortable with the tape recorder and did not give permission. In these cases notes were taken during the interview. Quotations from the interviews are presented unedited in the thesis and contain some venacular English.

5.4 Data Analysis

All the data gathered through the postal questionnaire, field visit notes and the transcribed interviews and notes were analysed. A four-fold typology of voluntary organisations emerged from the analysis together with an assessment of the level of involvement of disabled people in the organisation. A detailed analysis is provided in Chapter Six.

5.5 Data Validation

In order to validate the analysis of phase one of the field study findings two half day discussion sessions were held on April 9 and 16, 1994. Invitations were sent to all the 31 voluntary organisations. Nineteen people attended these (seven disabled people, two parents and the rest non-disabled persons). They were from ten organisations. The researcher presented the findings and analysis of phase one of the field study and received feed back from those present. These were very fruitful discussion sessions as the participants interacted openly and made valuable comments on the interpretations of the data gathered. An interesting development was the revelation of the difficulties faced by disabled people in their involvement in the political process. This revelation prompted the researcher to

examine the difficulties faced by SBM with the government in 1981 as described in Chapter Four. There was opportunity to clarify terms and concepts. Disabled people present were very vocal in their analysis and this was helpful.

The researcher published phase one of the findings in a booklet for popular readership (Jayasooria, 1994). All the 31 organisations received a complementary copy. This further illustrates the researchers' feedback to the organisations and especially disabled people in Malaysia in accurately reflecting their concerns.

6. PHASE TWO OF FIELD RESEARCH (MICRO)

6.1 Specific Research Focus

Phase two was a qualitative study of the models of social work practice identified in phase one through the indepth study of two organisations, one organised by non disabled people and the other organised by disabled people. For confidentiality reasons the names of the organisations are withheld and they will be referred to as charity care organisation (CCO) and self-help organisation (SHO).

6.2 Selection criteria for organisational study

The organisations could be divided between the 'for' and 'of' categories. This factor had a tremendous influence on the level of involvement of disabled people as well as the priorities identified. Therefore an organisation of and organisation for' were selected for the indepth study. Secondly, the organisations tended to specialise their services for specific groups of disabled people, for example, blind people or people with learning difficulties.

Therefore services organised to one particular group namely physically disabled people were selected.

6.3 Formal Approval Sought for Field Study and Involvement

Initial contact was established with CCO in the first phase of the field study when the researcher visited the organisation and met a senior elected official responsible. The researcher requested official permission to be a volunteer between August and December 1994 and this was granted. This enabled the researcher to have access to residents and records and to attend Committee meetings. One of the first assignments given was to assist in the preparation of the newsletter. The researcher was therefore introduced to the residents as a volunteer assisting in the preparation of the newsletter and doing a research project. Working on the newsletter provided a helpful introduction to the residents.

In the case of SHO the researcher has had a working relationship with one of the senior elected officials. A formal application for the field study for the months August to Dec.1994 was made and approved by the Executive committee. This enabled the researcher to attend Executive committee and sub-committee meetings, and access members files and SHO records as well as attending meeting of members in the Klang valley. The researcher was introduced to SHO officials and members as one undertaking a field study.

6.4 Participant Observation

William F. Whyte (1984) rightly identifies three approaches to participant observation: overt, semi-overt, and covert. The researcher adopted the overt approach. All involved in

the field study knew the role of the researcher. In so doing the researcher avoided the ethical problems of concealing the true intentions of the study.

Furthermore adopting this approach provided an opportunity to be actively involved in the organisations. It gave an insiders perspective. One possible draw back was that people on the whole would be guarded about what they shared with the researcher. However as the field study lasted from August to December 1994 and the researcher also had regular contact in an active way between January and April 1995 it was difficult to be guarded all the time. For example while having an unstructured discussion with one of the residents at CCO, she said in passing that she did not eat the food served in the home but bought food from outside. The next day when the researcher met her, she said

"Please don't tell the people in the office that I told you about my eating out. I don't want to be seen as saying that the food served was not good".

Over time relationships are built and people find it easy to open up especially during unstructured discussions. One elected official commented that there were two types of researchers, one who does research but is not committed to the cause and another who is one committed to the cause and is genuine. In his judgement this researcher was one of the latter and therefore received his support. Being a participant observer provided valuable opportunities for interaction with service users, staff and elected officials both formally and informally.

6.5 Data Collection - Field Visits

Between August and December 1994 the researcher made twenty-four field visits to the CCO. Regular visits were made after this period between January and April 1995. During

these visits which usually lasted between two and six hours the researcher had the opportunity to interact with residents and staff. Making oneself available to the residents provided valuable opportunities for interaction. The researcher found that unstructured discussion was very informative. The best discussions were on very informal occasions for example after a meal or after tea. A number of residents also requested personal assistance such as accompanying them to the post office, writing out cards and addresses, running down to town and purchasing something needed and, on one occasion, even assistance in retiring one to bed because the person could not wait for staff assistance. The researcher also found involving his wife and children helpful in establishing relationships because the service users were then more inclined to see the researcher as a normal human being and not just as a researcher. Many of the residents like to have fellowship with families. Little gifts such as toys and food items were given by the residents to the researcher's children. Often when the researcher visited alone, the residents enquired of the family and this became a good starting point for conversations.

In contrast the contact with the services at SHO was different. Nineteen visits to SHO office, and its members and officials took place during the field study period. This was in addition to the fourteen interview visits to the service users. The main difference was the residential nature of CCO where in one visit one met everyone especially during the meal times. By contrast at SHO each time it was a small gathering of disabled people.

6.6 Data Collection - Committees and Documentation review

The researcher had the opportunity to attend three of the five House and Welfare Committee meetings which were held at CCO during the research period. This provided

the insight into what kind of issues were discussed and the general tone of the gatherings. The researcher was granted permission to read all the minutes of the Council (four meetings held during the period), received copies of the House and Welfare Committee minutes (five were held) and minutes of the Residents Disciplinary Committee meeting (one was held during the period). Other documents include the administrative report, Annual General Meeting report and the staff daily report book (nursing book).

At SHO there were fifteen organised committee meetings during the research period (ie Executive Committee, Employment and Welfare sub-committees), of which the researcher attended twelve. Being a participant observer at these meetings enabled the researcher to gain a first hand experience of disabled people running it as well as an understanding of their main concerns in decision making. Opportunity was provided for the researcher to make comments or ask questions for clarification. Members were very open in this process. Over time relationships were built between the researcher and key elected officials and the staff. The staff have been very cooperative especially in making various documents available.

6.7 Data Collection - Interviews of Service Users

Twenty-eight service users were interviewed, fourteen from CCO (See Appendix 7) and fourteen from SHO (See Appendix 8). Anonymity is maintained. The primary objective of the interviews, as well as field visits, was to gather a personal account of the experiences and opinions of these service users. A service user's case study outline containing semi-structured and structured questions was used for this purpose (See Appendix 4). The interviews took place between January and March 1995. In the case of CCO the interviews

took place at the Home, however in the case of SHO it was either at their work place or their private homes which were scattered around the Klang valley. Prior to the interviews the researcher had gathered the background data of the service users from their case files kept by the two organisations. The interviews lasted between 1 hour and 15 minutes and 1 hour and 45 minutes.

The criteria for interview selection used in SHO were straight forward. During the months the researcher was involved as a participant observer (August and December 1994), the Employment sub-committee attended to twenty-eight cases of which nine were members from the Klang valley and the Welfare sub-committee handled thirty cases of which five were from the Klang valley. The researcher adopted those cases in the Klang valley and made field visits to meet these members and conduct the interviews.

In the case of CCO the selection was a little more difficult. The selection of the fourteen took account of race, gender, and age as well as the different employment categories they were involved in. This was done in order to compare this data with the fourteen interviewed from SHO, especially the employment categories (wage employed, self-employed, sheltered workshop and unemployed). Due to the nature of the service provided all forty-four residents were receiving assistance during the participation observation period (August - December 1994). Therefore from among the residents, the researcher identified nine residents who were in active employment of some kind (ie generating income) and four cases of a welfare nature in order to match the SHO sample.

The researcher was present in the key meetings when these cases were discussed and the field visits enabled the researcher to acquire feed back from the service user on the assistance provided as well as other matters.

It is acknowledged that there are a number of differences and difficulties in the two lists of service users, namely in terms of gender representation, racial composition and that while they are representative of service users in the respective two organisations, it might not be reflective of the national picture based on gender and race. The situation is further complicated when there is insufficient statistical data on disability in Malaysia.

There are similarities in that the service users from the two organisations are all physically disabled people, receiving assistance with welfare or employment needs during the field study period. The similarity and differences in these case studies reveals the nature of social work practice in the Malaysian context. What is essential is to draw from the indepth interviews, the type of assistance provided and the role played by disabled people in determining their need.

One difficulty the researcher faced was language, as a number of the service users spoke vernacular Malay or Tamil. The researcher has a working knowledge of both of these languages. Quotations from the interviews are presented unedited in the thesis and contain some venacular English.

6.8 Data recording and analysis

The researcher maintained a log book during the field study especially for writing up observations made during the field visits and participation at the different meetings. This was done immediately after each field trip. Notes were taken during the committee meetings. During the indepth interviews, notes were taken. In Phase One the researcher had used a tape recorder for a majority of the interviews. During the second phase a number of the CCO residents objected and therefore the researcher resorted to taking brief notes and key points said. A similar approach was adopted in all the SHO interviews. Whyte (1984 : 113) notes three mechanisms for recording interviews are possible, namely, the tape recording, note taking during the interview or writing notes after the interview is over. The second and third of these was adopted. In most cases in order to ensure a free flow during the conversation, key points or quotes were recorded and after each interview fuller notes were made.

6.9 Data Validation - Brainstorming and dialogue session

In both the organisations at the end of the field work there was the opportunity to discuss the data analysis with a small group of disabled people. These discussions or brainstorming sessions were very useful to further clarify the data gathered sharpen the analysis and check the interpretation. Furthermore, these gatherings have provided useful feedback to the two organisations on positive changes that could be introduced.

In the case of CCO, six of the fourteen interviewed met with the researcher on April 2, 1995. They made some very constructive and critical assessments of the home. However they requested that in the report of the meeting which will be made available to the Council

they should not be individually identified. A report of the gathering entitled 'Building the potential of residents' was forwarded to the CCO Council for appropriate action.

The brainstorming gathering at SHO was a major breakthrough as the Employment sub-committee formally organised this gathering to receive feedback. This was organised as a result of informal comments made by the researcher concerning some of the findings from the field interviews. A short one page comment entitled 'Moving beyond Employment Casework', was circulated prior to the discussion which took place on March 31, 1995. It was attended by six SHO members. The report of this gathering was discussed by the Executive committee in July 1995 with a view to implementing some changes.

6.10 Policy Input within voluntary organisations

At Phase two of the field study the researcher was called upon to make suggestions during the various committee meetings. For example, when the House and Welfare Committee at the CCO discussed staff leave, the researcher was asked to give input. However, the major involvement for change at the Home was in charting out an action plan to develop a community based service thereby moving beyond the residential home into the local community. In a newly established committee the researcher is now an elected official playing a direct role. The user group meeting report has been forwarded to the Home council for implementation. Here the Home will have to go through stages of change rather than a drastic one. In the case of SHO too the researcher has had opportunities to feed back the field study findings as a step to review the current programmes. Field study findings were presented at committee meetings when individual cases were reviewed. The report of

the group meeting has been circulated to elected officials who have agreed in principle to the suggestions. However they will have to identify the priority list for implementation.

In line with action research, the findings of the field study have been fed back to the service users and the elected officials. There is now a dynamic process of elaborating these suggestions and drawing out the stages for implementation. While this is a promising approach, in doctoral research the monitoring process is constrained by time. Nevertheless one can observe in the research process observation and evaluation, discussion and analysis, action and implementation. In the course of the field study the researcher together with service users and a number of the elected officials have gone through this process in one cycle. However in order to ensure dynamic change the cycle has to be repeated.

6.11 Continued Involvement

By the end of the field study period the researcher was appointed to various committees both at CCO and at SHO. In the case of CCO the researcher continues to play a direct role in two committees namely the Editorial Committee of the CCO Newsletter as well as the newly set up community based programme. At SHO the researcher was received as an Associated member and appointed a member of the *Employment sub-committee from* Jan.1995. These opportunities further enhance direct involvement alongside the disabled people in both organisations. During the employment sub-committee meetings between January - April 1995 the researcher was able to provide direct feedback from the field study interviews on the Klang valley cases being reviewed. In the case of CCO the researcher is providing input to assist the CCO be more community focused in their rehabilitation programme.

7. PHASE THREE OF FIELD STUDY (MACRO)

7.1 Specific Focus

In this third and final phase the focus was upon getting wider feedback on the Citizenship model on social work practice from a cross section of leaders from *the disabled people's* movement, and those from voluntary organisations committed to a social model of disability.

7.2 Data Collection - Qualitative

Fourteen leaders in the voluntary sector were interviewed (See Appendix 9). Of them eight are disabled people, two parents and four non-disabled persons. They represent eleven voluntary organisations. Once again anonymity of the interviewees is maintained. Each of them received a copy of the citizens model and were asked to give their comments on the paper. During the interviews the researcher received feedback of their opinions. Notes were taken during the interview and rewritten after that for analysis.

All those who were asked to give feedback on the Citizenship model of social work practice (See Chapter Three), also completed the Social Work Practice Questionnaire (See Appendix 5). A structured response was used to determine certain key aspects like hindrances for active involvement of disabled people and urgent priorities for strategic planning for the future joint action. This finding is documented in Chapter Ten.

7.3 Data Validation - Workshop

A half day workshop was organised on March 11, 1995. Invitations were sent to all the thirty one voluntary organisations in the Klang valley. Fourteen people participated (two

disabled people, one parent and eleven non-disabled people), representing seven organisations. Both the CCO and SHO which were part of Phase Two indepth field study were among the seven organisations. The researcher gave a brief presentation of the citizenship model and this was followed by discussion.

8. Chapter Conclusion

A variety of methods have been used to investigate the social work practice in voluntary organisations. The approaches adopted demonstrate the potential of combining both quantitative and qualitative methods to provide a comprehensive, as well as in depth study of voluntary action among disabled people in the Malaysian context. This approach has integrated macro and micro levels of analysis. It is further possible for us to note the potential of a collaborative approach where non-disabled researchers work alongside disabled people in a participatory way. The study has also demonstrated the action dimension of the research where the findings are fed back to the leadership of voluntary organisations to influence change.

The analysis of the findings will be the focus of the next four chapters, which will draw from both the micro and macro dimensions of the study. Prior to an indepth study of the approaches, a comprehensive analysis of voluntary action will be provided in the next chapter. These will provide the context for critical analysis of the citizenship model of social work practice in Chapter Ten.

DISABLED PEOPLE AND KLANG VALLEY VOLUNTARY ORGANISATIONS

1. Chapter Introduction

Chapter Four provided an overview of social policy and service developments for disabled people at a national level in Malaysia, as well as a general introduction to the role of voluntary organisations. It was noted in that chapter, that while the State provides some services, there is a heavy reliance upon the voluntary sector. Siti Hawa Ali (1994) recognises that voluntary organisations play:

an instrumental role in supporting and providing some of the services which are either limited or not well provided by the government. (Ali, 1994:1).

She goes on further to say that this sector is

a major player in generating public awareness and conscientizing the general public on social issues (Ali, 1994:1).

A similar conclusion is drawn by Wong Poh Wan (1993) in her study of early intervention programmes for children with learning difficulties. She notes:

Voluntary organisations continue to provide the bulk of provisions and services for the education of people with intellectual disabilities. (Wong, 1993:13)

This analysis is further verified through the empirical study carried out on voluntary organisations in the Klang valley and these findings are the focus of this chapter.

An earlier account (Jayasooria, 1994c) provides a comprehensive summary of the findings and serves as a useful point of reference. Details of the Klang valley which is the location of the field study were explained in Chapter Five. This chapter provides a critical analysis

of voluntary organisations serving disabled people in the Klang valley from the citizenship framework. Among the major foci of Chapter Six are an analysis of the different types of services provided, a four-fold typology of voluntary organisations, and a discussion of the barriers and opportunities to disabled people's involvement in voluntary organisations. Much of the chapter is written in a form of comparison of organisations set up by non-disabled people referred to as 'organisations for' and those set up and run by disabled people referred to as 'organisations of'. This analysis provides the context for the in depth analysis of the different models (in Chapter Seven and Chapter Eight) which emerge from the analysis in this chapter. We finally return to a comparative analysis of the models from the citizenship perspective in Chapter Nine

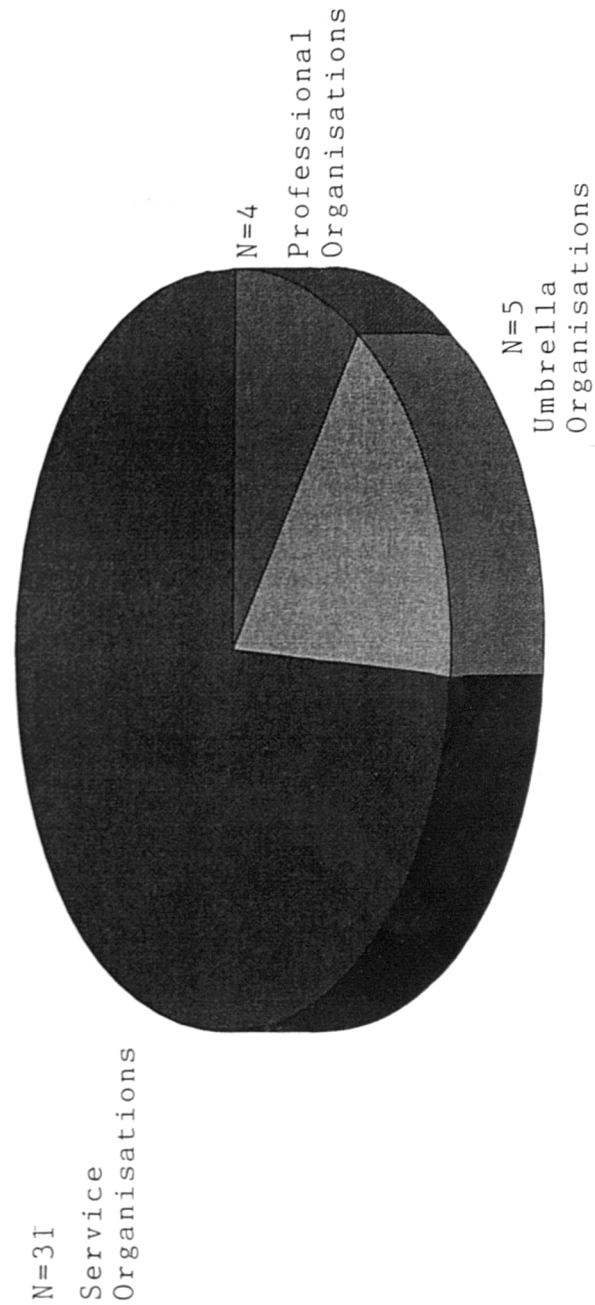
2. OVERVIEW OF VOLUNTARY ORGANISATIONS

In the Klang valley there are forty two voluntary organisations serving disabled people. Of these seven are *national umbrella bodies*, that operate at a national level and are based in the Klang valley, four are *professional staff organisations* and the remaining thirty-one *direct service providing organisations*. (See Figure 4).

2.1 National umbrella organisations

Earlier in Chapter Four we discussed some of the issues and difficulties faced by coordinating agencies in Malaysia. All the coordinating agencies operate from the Klang valley. Five of the umbrella organisations are single disability umbrella organisations. Of these, two organisations namely the National Council of the Blind Malaysia and the National Council for Hearing Impaired Persons include both 'organisations of' and 'organisations for' as members seek to bring effective coordination for the services they

Figure 4 : Organisations in the Klang Valley



provide to their respective service users. The remaining two are cross disability umbrella organisations. The Malaysian Council for Rehabilitation (MCR) has both national 'organisations for' and 'organisations of'. The Malaysian Confederation of the Disabled (MCD) on the other hand accepts only national organisations of disabled people. The MCD is the only umbrella body of disabled people in Malaysia.

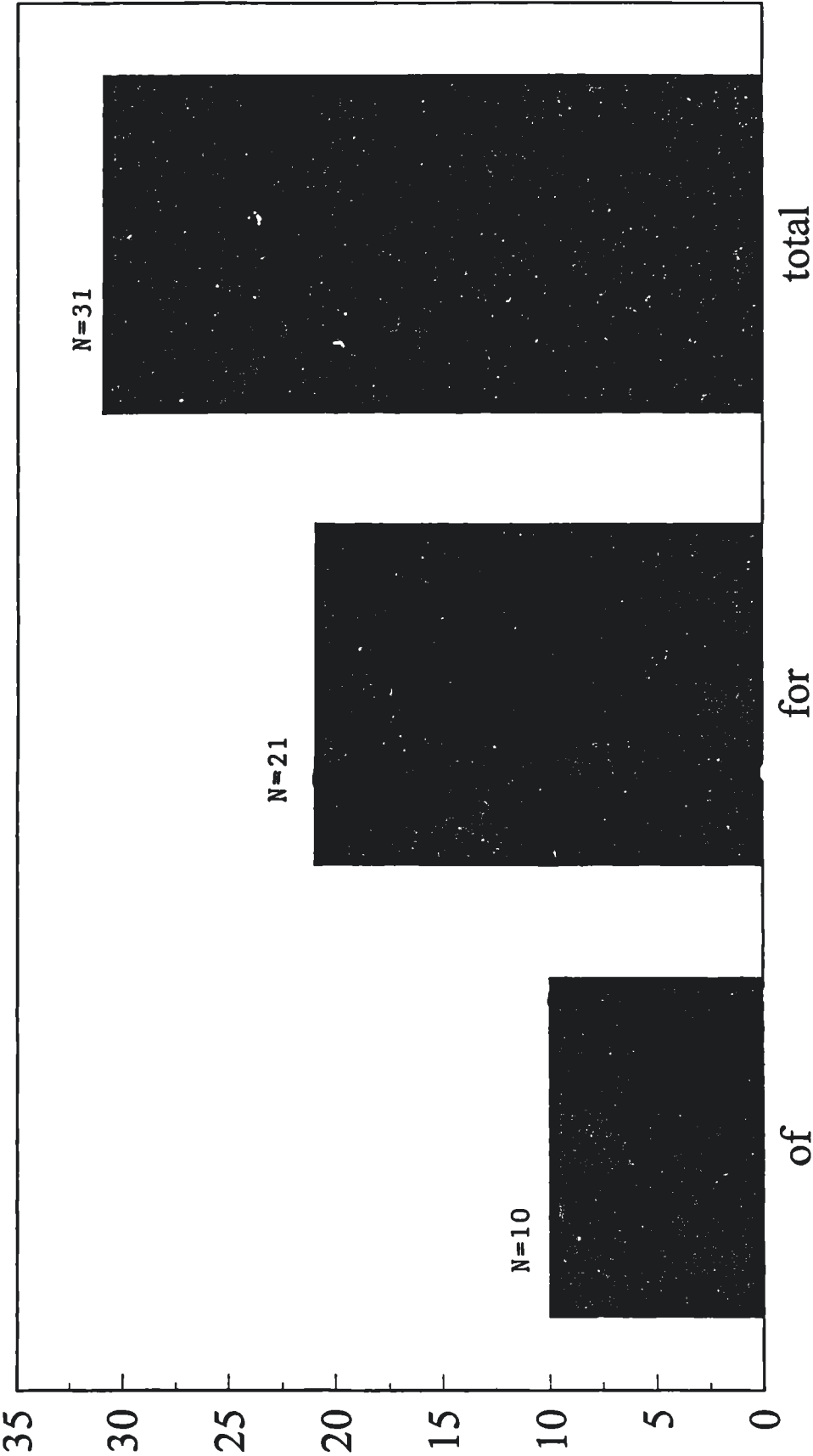
2.2 Professional staff organisations

There are currently four professional organisations operating from the Klang valley, providing support to service staff like social workers, occupational therapists, speech therapists and physiotherapists. Professional development of service staff related to disability work in Malaysia is still underdeveloped. Figures in 1992 reveal that there are only 182 physiotherapists and the ratio to the population is 1: 102,232 as compared to doctors is 1:2410 (Malaysia, 1993 :23). Figures provided by the different associations also indicated this for example the Orthopaedic Association has 157 members, the Occupational Therapy Association, 128 members only.

2.3 Direct service providing organisations

Thirty one of the organisations are direct service providing organisations. Some of these are national bodies but have active services and members in the Klang valley. Of the 31 organisations, 10 are 'organisations of' disabled people (organised by disabled people), whereas the remaining 21 are 'organisations for.' (organised by non-disabled people for disabled people). (See 5 and Appendix 1). Services therefore are dominated by non-disabled people organising services for disabled people.

Figure 5 : Direct Service Providing Organisations



Both Oliver (1990) and Drake (1992) identify ‘organisations of’ as those with at least 50% of the management committee being disabled people. All the organisations set up by and controlled by disabled people in the Klang valley, admit only disabled people as full members. Non-disabled people are accepted as associate members but they do not have any voting rights nor can they hold office. Only in the case of the Society of the Orthopaedically Handicapped (POCAM) is provision made for non-disabled people to hold office but he/she is nominated and elected by disabled people. ‘Organisations for’ or those currently controlled by non-disabled people do not have any constitutional restrictions. However, in practice they have not kept an open membership principle. In a majority of organisations membership is tightly controlled and in practice it is often by invitation rather than open application. Disabled people are not encouraged to participate. We will discuss this more fully later in this chapter.

3. DETAILED ANALYSIS OF DIRECT SERVICE PROVIDING ORGANISATIONS

3.1 Target groups served

The direct service providing organisations are categorised into two categories. Ten of these are organisations set up and run by disabled people and they cater for 1,733 disabled people living in the Klang valley region. The remaining thirty-one are organisations set up and run by non-disabled people, serving 1,808 disabled people in the Klang valley region. The total number of persons served in the Klang valley is 3,541 disabled people. (See Figure 6 and Table 3).

Figure 6 : Service Users

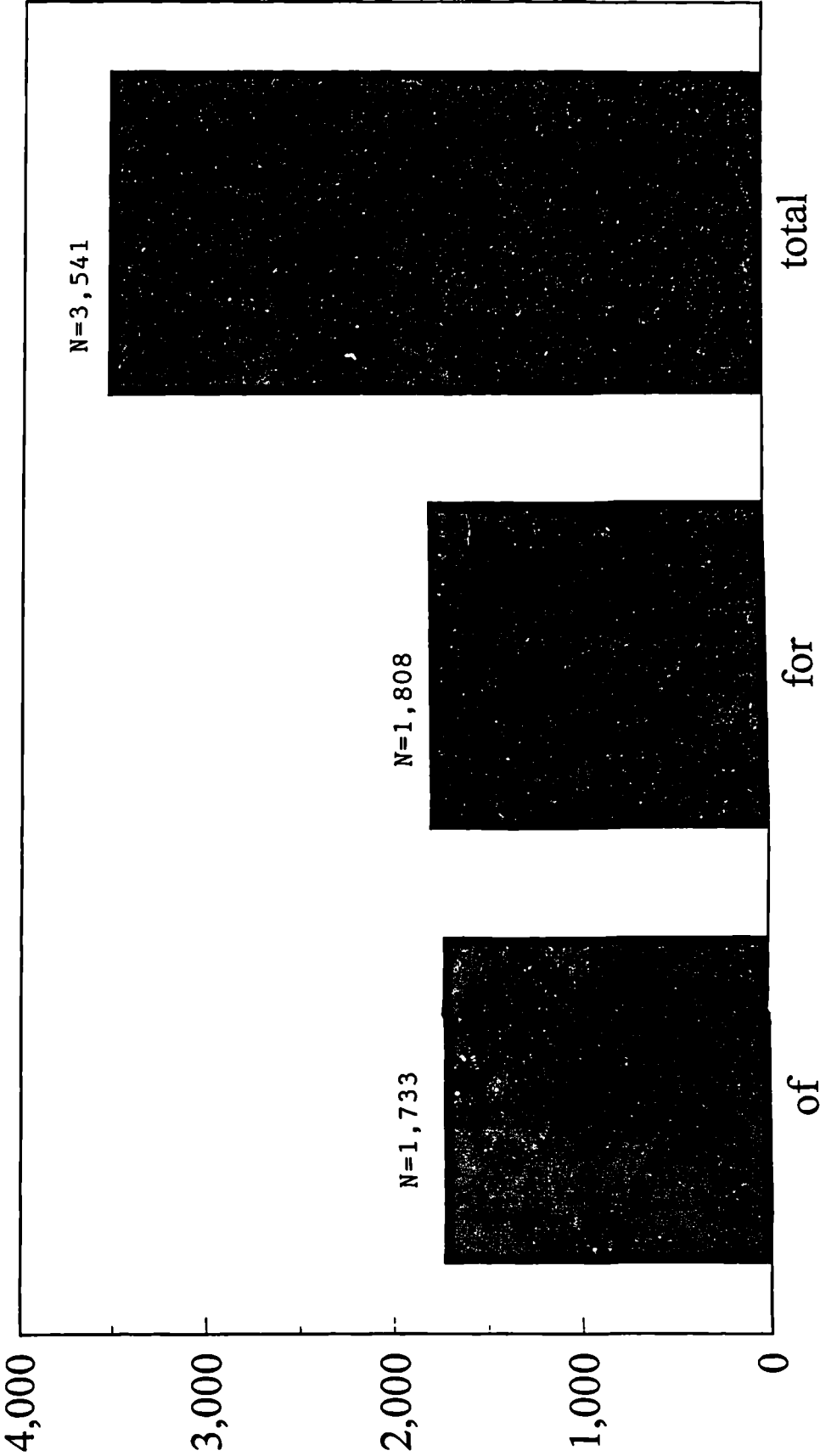


Table 3 Voluntary Organisations and Service users

Organisations	Number of Organisations	Number of service users
OF	10	1,733
FOR	21	1,808
Total	31	3,541

A majority of both ‘organisations for’ and ‘organisations of’ use medical categories in the name of their organisations. See Appendix 1. The medical categories and terminologies are dominant in Malaysia as in other parts of the world.

In Chapter Three and Four we noted the objections raised by Oliver (1990), Barnes (1991), Jenny Morris (1993) and Sally French (1994). They conclude that these categories are based upon medical or social construction and divorced from the direct experience of disabled people (Oliver, 1990 : xiv). The objection raised is an important one and it is essential to understand the issues faced by disabled people as a whole rather than in the traditional labels. Furthermore in doing so, one is consistent with the social model of disability. However the difficulty in the Malaysian context is that these are the very categories that both disabled people and non-disabled people in Malaysia use. Indeed even the organisations controlled by disabled people currently use these categories. For example, the Society of the Blind, Malaysia or the Society for the Orthopaedically Handicapped. These will continue to remain dominant in the developing world unless international agencies like the World Health Organisation and the United Nations adopt the alternative terminologies advocated by Disabled People’s International. Drake (1996) in his study of

voluntary organisations in Wales while noting that the categories such as physical impairments and learning difficulties are an artificial division, nonetheless uses them to ensure representation of data from a broad range of voluntary activity

3.2 Single and Cross disability organisations

Single disability organisations are by far the largest in number in contrast to cross disability organisations. (See Figure 7). Once again the traditional labels are in operation and services are directed to specific target groups according to the nature of the impairment.

3.3 Founding years

Oliver's (1990 : 113) analysis of the rise of voluntary organisations linked with the rise of capitalism is similar to that of the Malaysian experience. Disability related service in the Klang valley is a very recent development as 19 out of 31 organisations were set up in the last 12 years especially in the context of the improving economic position and the process of industrialization on which the country has embarked. (See Figure 8)

This is also the case when we look at the founding years with regard to 'organisations of', as 6 of the 10 organisations were set up since the 1980s. The 1981 International Year of the Disabled Persons (IYDP), as well as the UN Decade for Disabled Persons (1983 - 1992) brought greater awareness of disability issues. Along with this the Malaysian government policy on 'the caring society' and the role of the media have assisted this process. The impact of the UN Decade and policies, as well as the Caring Society emphasis was highlighted in Chapter 4. It is interesting to note that blind people were the first to organise their own services. They set up the Society of the Blind (SBM) in 1964. The

Figure 7 : Single and Multi-disability Organisations

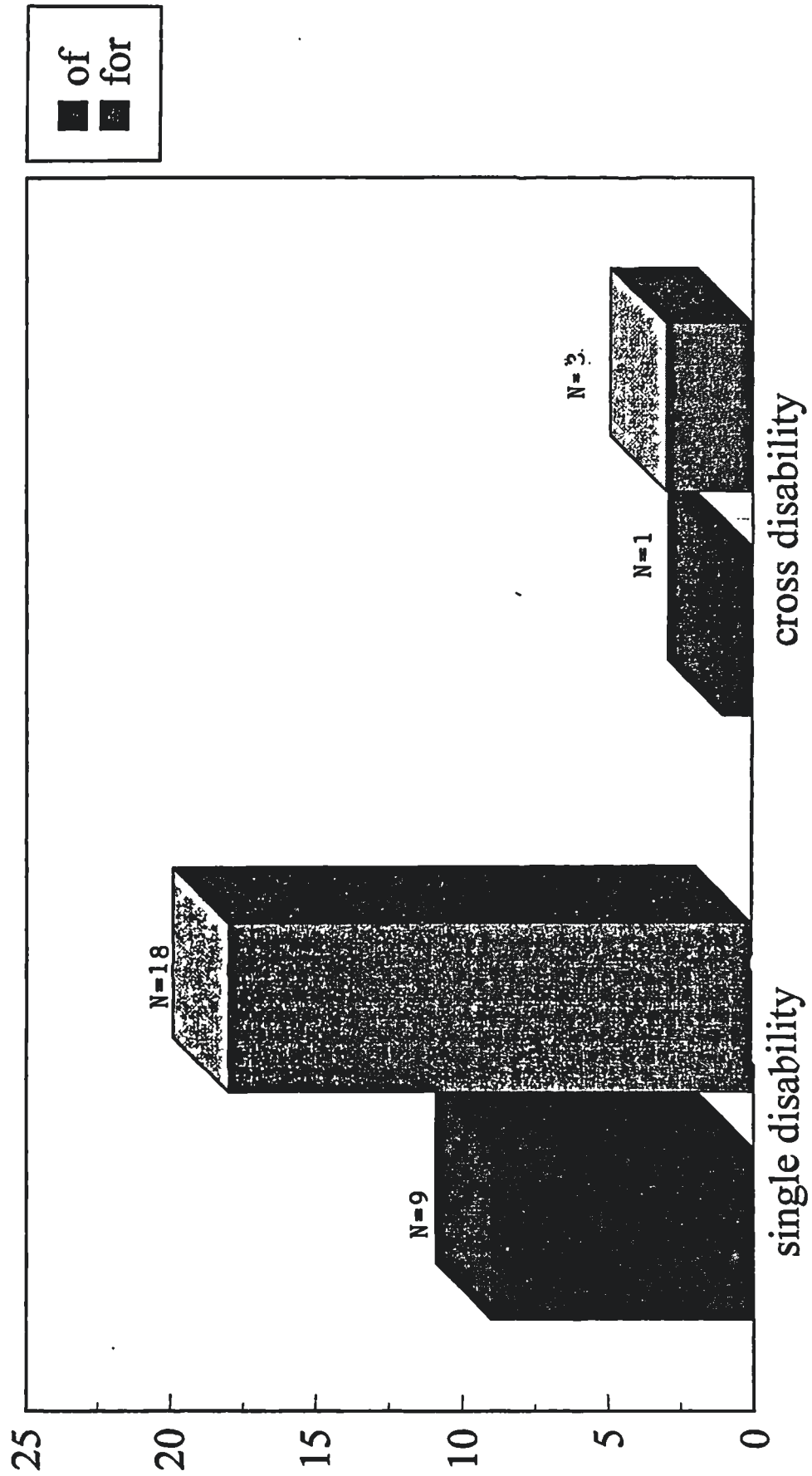
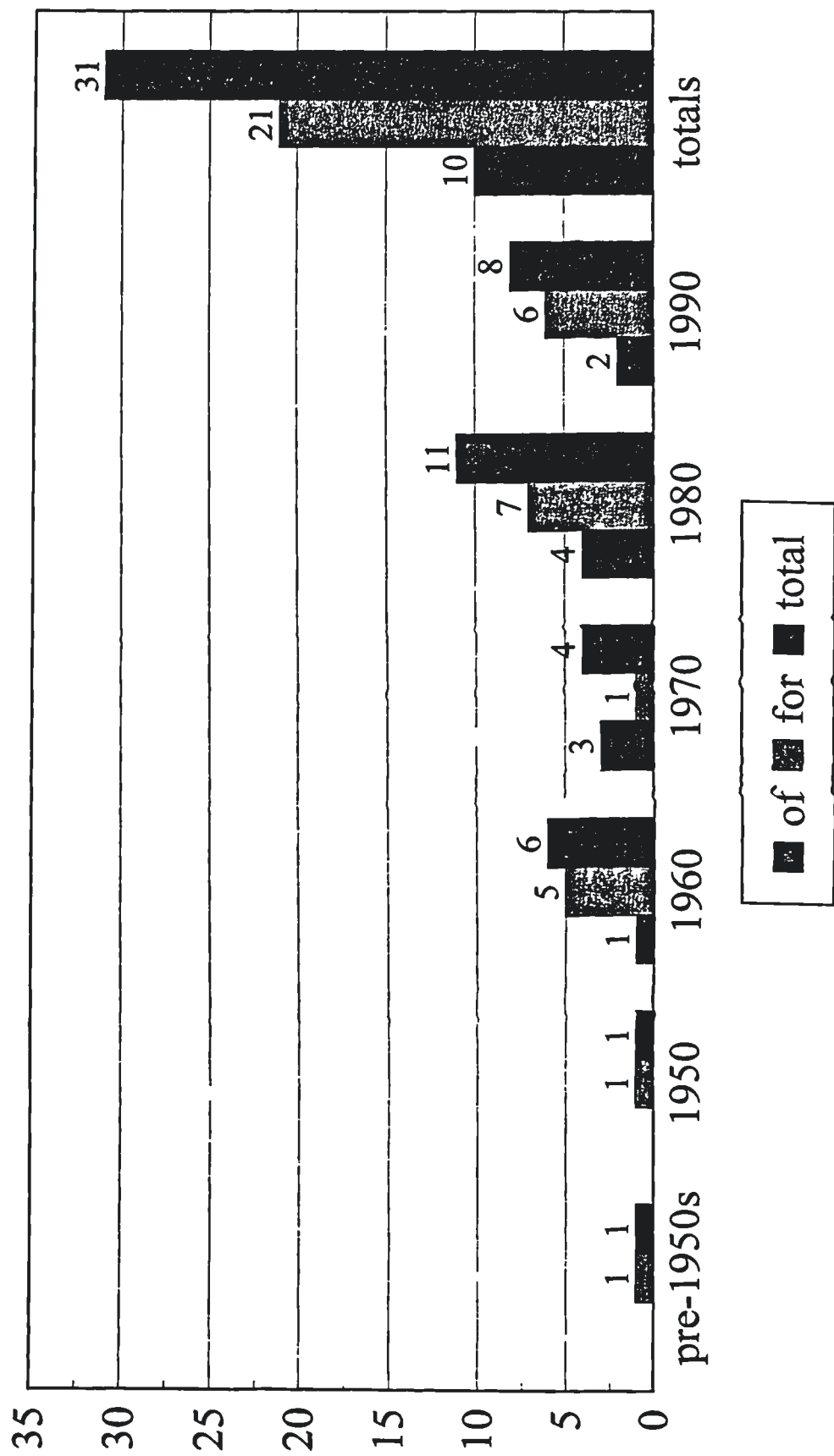


Figure 8 : Organisations by Founding Years



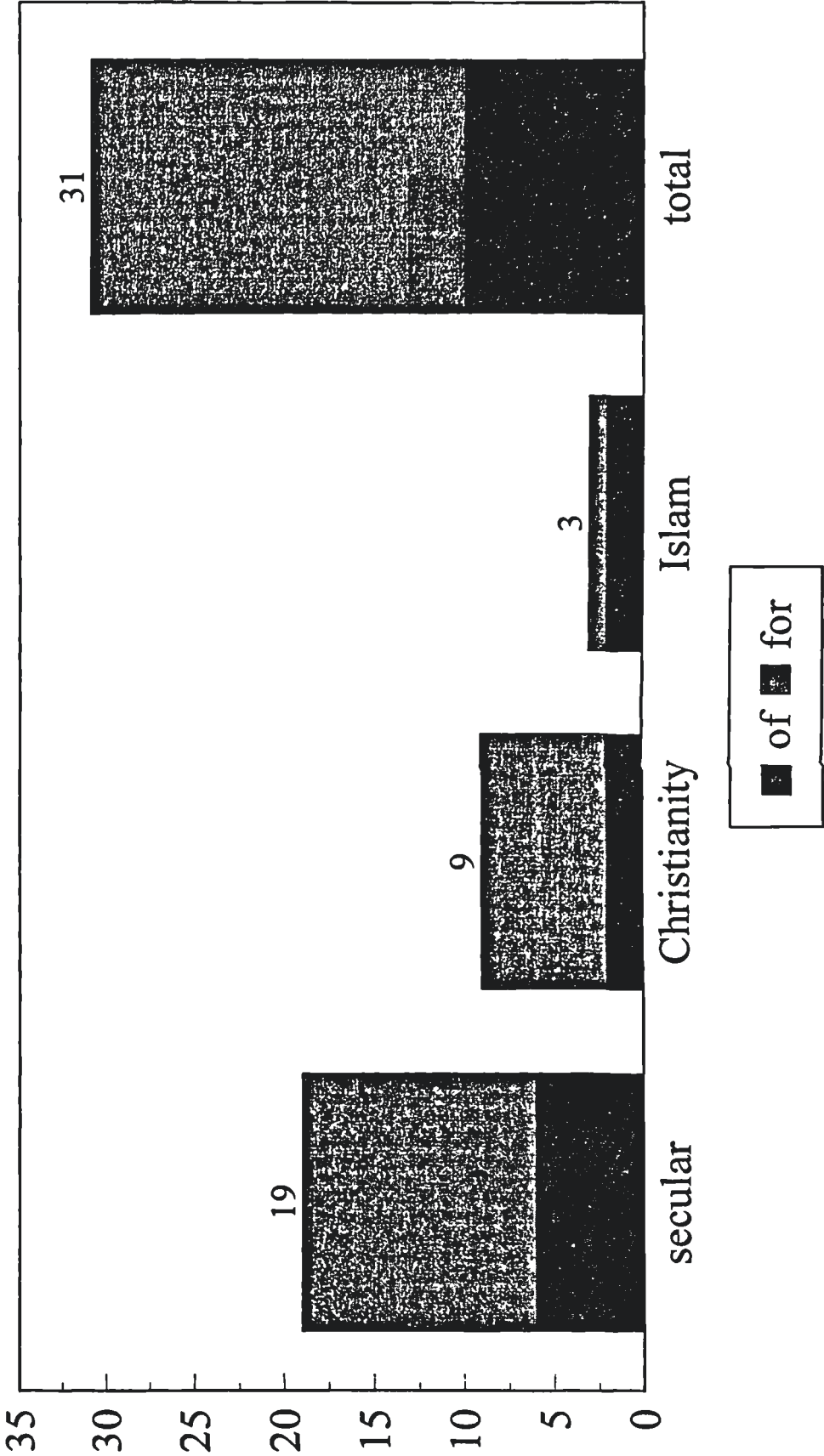
1970s saw the establishment of three other self help organisations by disabled people themselves. The founding president of SBM in one of the group discussions highlighted to the researcher, the objections raised by non-disabled service providers. These blind people were branded as radical because they were asking non-disabled people to give them the opportunity to serve in the committee and when they were refused the blind people set up their own organisation. In the early years there was some tension till the blind people initiated the formation of the National Council for the Blind Malaysia (NCBM) where both organisations of disabled people and non-disabled people joined forces. This is indeed a positive move and the NCBM president is a disabled person from SBM. The Malaysian Association for the Blind (MAB) has since 1989 employed a number of blind people to executive positions but membership and electoral office is still tightly controlled.

3.4 Organisations by religious affiliations

19 out of the 31 organisations are secular and humanitarian organisations whereas 9 are Christian based and the remaining 3 are operated by Islamic groups. (See Figure 9). As noted in Chapter Four early Christian missionaries from the Roman Catholic Church and the Church of England were the pioneers. However over the years other groups like Malaysian Christian Association for Relief (Malaysian CARE) and the YMCA have pioneered innovative approaches. The Christian Church has had a long tradition in service provision and have been in the forefront of developing services to disadvantaged groups in Malaysian society. (Hunt, 1989)

Islamic groups are newcomers in direct service provision to disabled people in the Klang valley especially in providing organised services such as residential and day care services.

Figure 9 : Organisations by Religious Affiliations



Mohamed Ariff (1991) highlights Islamic institutions through the provision of financial aid through the *zakat* (obligatory levy) to needy Islamic families which would include poor families with disabled people.

Other religious groups like the Hindus and Buddhist have not organised formal services but as a group generally provide voluntary and financial support to other voluntary organisations.

3.5 Full time staff

23 out of the 31 organisations together employ 337 full time paid staff. Of these 36 are disabled people.‘Organisations of’ employ only 8 staff of whom 6 are disabled persons. (See Figure 10). A fuller discussion on this theme is provided later in the chapter.

4. SERVICES PROVIDED BY VOLUNTARY ORGANISATIONS

The services provided by the organisations are classified into nine main categories as shown in Table 4. The categories are not listed by order of priority but alphabetically. These categories reflect the major services provided by the organisations.

Figure 10 : Staff Employed by Organisations

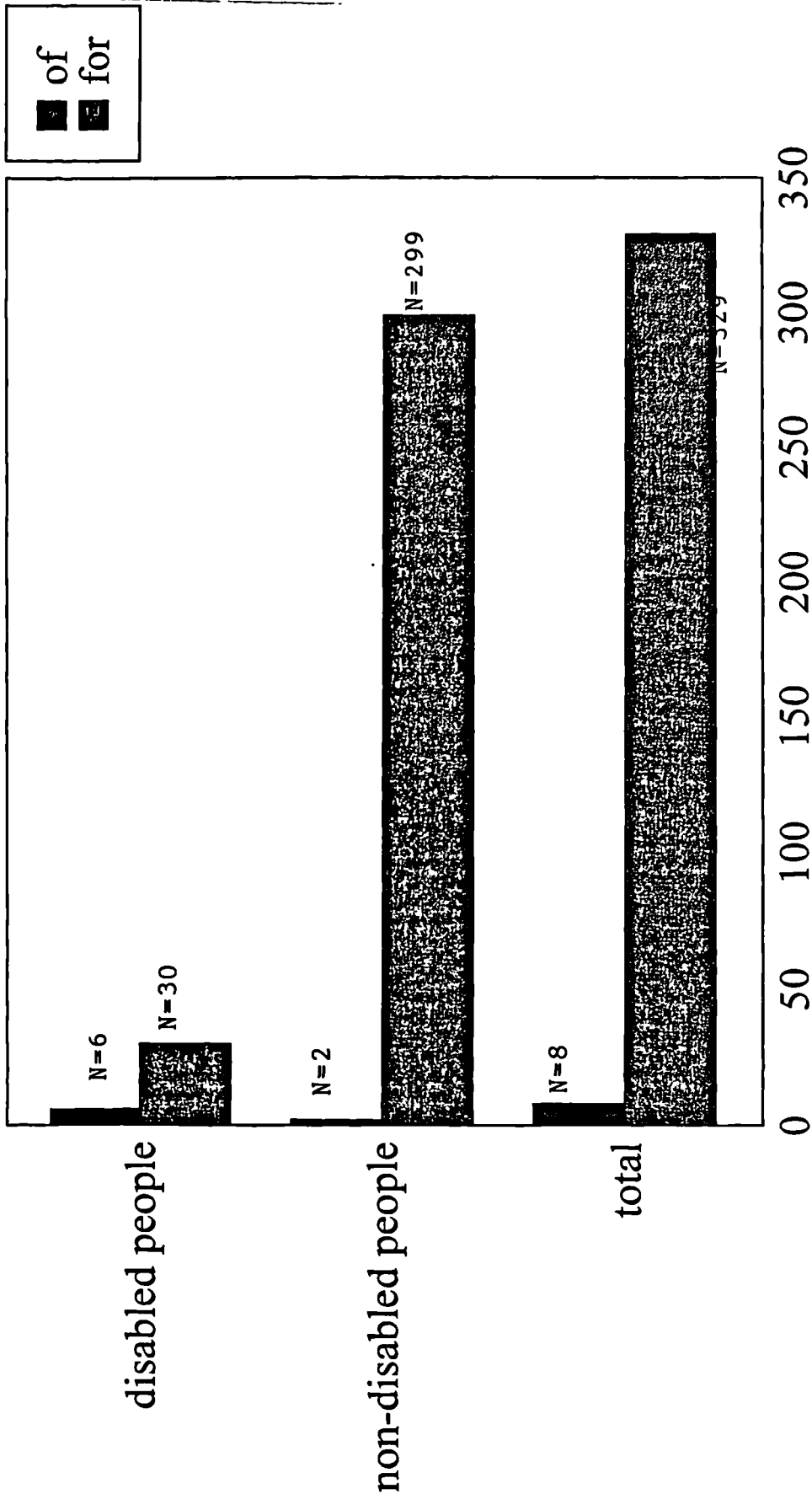


Table 4 Services provided by the Voluntary Organisations

Type of Services	Organisations OF (N=10)	Organisations FOR (N=21)
Community Action	6	6
Day Care	-	6
Education and Training	2	12
Employment	2	12
Personal Services	7	5
Public Awareness	4	9
Religious services	4	-
Residential Care	-	6
Social Programmes	7	3

A majority of the voluntary organisations run more than one service and therefore most of the 31 organisations are multi-service-providing organisations. Two major areas of focus by the 31 'organisations for' are educational and training services and personal services. The third major area is community action or attempts to influence the policy process for change as indicated by 35% of the organisations.

It was interesting to note that there is a clear difference in the priorities set by 'organisations of' as compared to 'organisations for'. The three main services highlighted by 'organisations of' are personal service (indicated by 7 out of 10), social programmes (indicated by 7 out of 10) and community action (indicated by 6 out of 10). In contrast 'organisations for' three key areas of services are education and training

(indicated by 12 out of 21), public awareness (indicated by 12 out of 21), and employment services (indicated by 9 out of 21).

4.1 Community Action

The purpose of community action is to influence public policy and advocate changes in society within the constraints of democracy in Malaysia. These constraints have been discussed in Chapter Two and Four. Nonetheless there are opportunities and some organisations seek to bring about policy changes from within the political environment in Malaysia. More of this will be discussed in Chapter Ten. In this context more ‘organisations of’ (6 out of 10) as compared to 6 out of 21 ‘organisations for’ are involved in community action. The key strategy is through dialogues with relevant Government agencies, submission of memoranda and press releases.

4.2 Day Care Services

Day care services are run by six organisations for disabled persons. A majority of these cater for people with learning difficulties. This is an essential service as in the urban areas both parents of people with learning difficulties might be working. Currently none of the ‘organisations of’ provide day care services. One possible reason as explained by some disabled people is the resources needed both financial and personnel to run such centres. Others on the other hand note that ‘organisations of’ concentrate on advocacy rather than in service provision.

4.3 Educational and Training services

As indicated earlier 12 out of the 21 'organisations for' run this service. Examples are a formal school run for the deaf, and an informal school and training groups provided for people with learning difficulties. People with learning difficulties are the most neglected ones with regard to statutory or government provided educational and training opportunities but the voluntary organisations are providing this valuable service. Many of these programmes are very creative and relevant to real life issues. They are oriented towards living skills and are radically challenging traditional notions of education. One service staff member employed in such a programme, soon an interviewee explained that the training programme promotes independence for people with learning difficulties by helping each of them:

“to reach their potential as an individual. That will build up their self-esteem so that they can do things for themselves or at least with a bit of support rather than people doing things and changing them as just totally unable”.

2 out of the 10 'organisations of' run this service however the focus in this case is more towards leadership development.

4.4 Employment Services

A rapidly industrialising country provides numerous opportunities for employment. For disabled people the transition from economic dependency to financial independence, is often by acquiring skills and an opportunity to earn a living through a job. An earlier account (Jayasooria, 1994c) provides a useful description of the different voluntary and private sector attempts. 'Organisations for' lay some emphasis on this as indicated by 9 out of the 21 voluntary organisations. In the case of the Malaysian Association for the Blind (MAB) they run a vocational training centre together with a placement service for blind

people. Other agencies like the YMCA self reliance centre have set up businesses owned and run by deaf people. The YMCA provided a loan for the purchase of the equipment necessary for a launderette. Over a few years the disabled people were able to repay the loan and are currently making a small profit for the business venture.

Private sector companies as a result of the campaign launched by the government (referred to in Chapter Four) have responded positively by providing employment opportunities to disabled people. Some of the voluntary agencies have taken advantage of this by placing disabled people in open employment. Sheltered workshops have been set within the existing premises of voluntary agencies to provide some training. At the Spastic centre contracts are acquired, for example cleaning head phones and repackaging them for the national airlines and a group of disabled people are paid a daily allowance for work done. In Chapter Seven some experiences of disabled people working at sheltered workshops is discussed. A number of voluntary organisations have disabled people doing handicraft work and in the case of others it is providing support services to industries, for example, packaging. Only 2 of the 10 'organisations of' provide assistance to members. In both these cases small grants are provided together with letters of recommendation to help them start or expand small businesses. Experiences of disabled people in small business is discussed in Chapter Eight. Jayasooria (1995) also provides an analysis of small business development among disabled people.

4.5 Personal Services

One major focus of the 'organisation of' is the provision of direct personal services to members. This includes providing a letter of recommendation for a job, counselling

support, and financial assistance in case of emergency. In the case of 'organisations for' the focus centres around home visiting and counselling support when required, 5 out of 21 'organisations for' provide this service. Unlike the United Kingdom there is no support for home assistance or meals on wheels provided by the voluntary or public sector.

4.6 Public Awareness

The mass media have played a key role in publishing not only the work of voluntary organisations but also educating the general public about the needs and problems of disabled people. Most of the organisations have been featured in the media which also has a positive effect on fund raising. Both 'organisations of' and 'organisations for' have devoted time to this. Often public awareness programmes are organised as in the case of the YMCA Centre which organises an annual deaf awareness week. A distinction has been made between public awareness and community action as in the latter there is an attempt to directly lobby for policy change.

4.7 Religious Services

While there are 12 organisations which have a religious affiliation only three of them provide a direct religious service. Examples of religious services are making religious material available in Braille or conducting prayers, religious instruction and programmes. All three religiously based 'organisations of' provide direct religious programmes to their members. In this case all three cater for the blind. It is very striking to note that in the case of the 'organisations for' none of the eight with a religious affiliation run religious programmes. In this case religion serves as the motivational experience for involvement among disabled people. Both in the case of the seven Christian based organisations as well

as the one Islamic organisation, these services are provided to disabled people irrespective of race or religion.

4.8 Residential Services

Only six 'organisations for' disabled people provide accommodation along with other services. For example, MAB and the Society for the Rehabilitation of the Disabled provided hostel facilities for the trainees at their short-term vocational training programme. However Cheshire Home and Ashmara Cahaya provide long term residential services for a limited number of residents. Malaysian CARE which used to run a long term residential service has now converted it into respite care to provide short term stay for training or for the relief of families.

4.9 Social Programmes

Social programmes are high on the agenda in 'organisations of'. This is indeed revealing as disabled people do not have much opportunity to socialise. Often the non-disabled community is insensitive to the social needs of disabled people. The Society of the Chinese Disabled Persons in Malaysia often organises a dance for both disabled persons and non-disabled persons. Only 3 out of 21 'organisations for', cater for this need. In the case of the programmes organised by Malaysian CARE they organise social clubs for people with learning difficulties. Attempts are being made to develop the leadership skills of the people with learning difficulties to eventually run their own programmes with limited support from the staff.

5. INVOLVEMENT OF DISABLED PERSONS IN ORGANISATIONS 'FOR'

One major indicator of whether an organisation is empowering disabled people is to examine the mechanisms provided for disabled people's direct involvement in the identification of needs, decision making, elected office and policy formulation. This aspect was clearly outlined in the Citizenship model of social work practice. Godfrey Ooi (1993) highlights this principle concerning the direct involvement of disabled people and acknowledges that

little effort is being made to bring the disabled into the decision making and planning process in work concerning their welfare and well-being. (Ooi, 1993:23).

Ling (34) a disabled person and an activist in the disability movement describes this reality where involvement is defined by non-disabled people in a selective way.

"All of them [referring to non-disabled people] I should say come up with a good heart to help the disabled people... They do really do some good things. I can't be too bias to say that they are not. But I have a lot of reservation for the agencies or the associations for the disabled people. The main reason I notice is that when they need whatever money they will always push the disabled people to the front line, to the limelight, to the media. But after raising enough money, the disabled people were not invited to sit in the committee to discuss how to use the money. When in terms of using money, it is always the able-bodied dominated it and to decide".

Another disabled person interviewed, Hasan (31) noted:

"All these organisations [referring to 'organisations for'] carry the flag of the disabled person, but they did not encourage more participation from the disabled".

Table 5 provides a summary under four crucial indicators namely involvement at the point of formation/founding, holding elected office, opportunities for dialogue for service users and finally opportunities in full or part-time employment. The analysis here is on 21 'organisations for'.

Table 5 Involvement of disabled people in 'Organisations For'

	Number of Organisations (N=21)	Number of service users (N=1,808)
Involvement in founding	2	4
Holding electoral office	3	5
Dialogue and feedback sessions with service users	3	270
Full-time paid staff	4	30

5.1 Involvement at founding

At the point of founding only 2 out of the 21 'organisations for' had the involvement of four people. In both these cases the disabled people are non-service users and are professionals.

5.2 Holding elected office

Of the 21 organisations only three organisations have five disabled people holding elected office. In the case of two of these organisations the disabled people are professionals and well placed in society. In the third organisation direct service users are members of the management committee running the YMCA deaf self-reliance centre. It can therefore be concluded that all but a tiny minority of the 1,808 disabled people served by 21 organisations are not directly involved in the decision making process.

5.3 Policy on the involvement of disabled persons in the organisation

Of the 21 organisations only one organisation (YMCA Self-reliance centre) has indicated it has a clear policy on the involvement of disabled persons in the running of the organisation. This organisation too has put this principle into practice by the direct involvement of deaf persons in the management committee. 4 persons out of the 8 in the committee are disabled people. Their policy statement on participation is clear:

to facilitate the full participation of the hearing impaired and to enable them to exercise their rights as citizens. (Yip, 1990:2)

With regard to the decision making process the organisation indicates that it has " provided places in decision-making committees, employed hearing impaired staff." (Yip, 1990:2)

5.4 Employment of disabled people

Of the 21 organisations only 4 organisations employ a total of 30 disabled people. There is no breakdown of the type of role played by these people and what percentage of them hold executive positions in the organisations. Of the disabled people employed ten are blind, nine hearing impaired, one Orthopaedically handicapped and the remaining ten have a learning difficulty. A striking feature is the employment of the ten disabled people with a learning difficulties by the Selangor Association for Retarded Children as 'teacher assistant' with a salary of RM75.00 for half days work in the month and RM150.00 for a full days work. Employees Providence Fund (EPF) contributions are made by the organisation.

5.5 Dialogue and Feedback with service users

Only 3 out of the 21 organisations have organised a consumer dialogue programme. By this is meant, a formal time during which there is opportunity for the service users to express their opinions and suggestions as well as raise their problems. One of the 3 organisations namely MAB organised a large one off gathering during which time 200 of their service users presented their view points and suggestions for the improvement of the service. A consumer dialogue subcommittee was set up comprising 5 blind people. Although the dialogue was well attended and an extensive report prepared, MAB has not implemented the findings. Cheshire Home conducts a monthly residents' meeting which is attended by about forty residents. It provides an opportunity for the residents to highlight their problems to the committee. In the case of the YMCA deaf self reliance centre there is also a monthly gathering of about 30 of the members who provide input and feed back on the services and programmes provided.

5.6 Reasons for the lack of involvement

A number of reasons can be cited from actions of non-disabled people to discourage participation to practical reasons. Hasan (31) a disabled person who was interviewed and who served as a committee member in an 'organisation for' commented :

"they [referring to non-disabled people] have already put hard way for the disabled to come in their society. For example, through high membership fees. When you want to get votes, from who else you expect? So you must expect from your friends, from your colleagues, who are also disabled but they are not members because of the high membership fees. And then also, they put rules that no questions to be asked during the AGM, they should write earlier to the secretary in two weeks' time so that during the AGM... not on the spot questions. I think next AGM I want to write to allow on the spot questions also. This is also discouraging".

Another disabled person Ahmad (42), who is an executive staff in an organisation for' and a member of an organisation of', said:

Maybe there are many factors to it. It cannot be only one. At the moment, the chief tickets are still held by people who have been there very long. So they are not going out and some new opportunities are not created. Number two is, very capable disabled people are not interested to come back to the organisation... Other factors, may be there is still the negative feelings from the organisation structure towards disabled people, whether they can do it or they may not be able to do it".

Three possible reasons could be further summarised from the data gathered concerning the lack of involvement of disabled people in 'organisations for'. Firstly, it is indicated that active involvement depends on the target group served. About half of the 'organisations for', serve people with learning difficulties it is difficult for them to incorporate them into electoral process and in the decision making process in running the voluntary organisations. Out of the 21 organisations, 10 provide services to this group. Elsewhere the researcher (Jayasooria, 1993b) in discussing self-advocacy groups has affirmed that people with learning difficulties must be provided with opportunities for involvement in decisions that affect them. Involvement of people with learning difficulties in decision making is often denied or ignored because of the nature of their impairment. It must be noted that some of these organisations have parents or family members in elected office and playing a key part on behalf of their disabled relatives.

Secondly, it is possible to note that 'organisations for' tend to over rely on full time staff. Figure 10 reveals the glaring difference in this aspect between 'organisations for' and 'organisations of'. The 21 organisations employ 98% of the total 337 fulltime paid staff employed in the Klang valley. 'organisations for' tend to rely on full time staff in contrast to 'organisations of' which are self-help groups. Midgley (1981) provides a critical

assessment of the professional domination in social work and Oliver (1983, 1991) comments specifically upon disabled people. In the Malaysian context a majority of the staff have only basic training but within an underdeveloped professional context, full time staff with what ever formal qualifications are regarded as 'experts' and can exert control over disabled people. This is clearly illustrated in Chapter Seven.

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Thirdly, the orientation to voluntarism in the Malaysian context could be a major contributing factor to hinder active involvement of disabled people. The prevalent view of charity or caring can be seen to be a major obstacle for the active involvement of disabled persons. The dominant view is one of 'doing for the other' rather than one which enables and empowers service users. There is an attitudinal problem and non- disabled people are not developing the leadership potential of disabled people. It could be argued that the current leadership in 'organisations for' are the major obstacle to the dynamic involvement of disabled people. This attitudinal problem leads to structural issues which institutionalise the exclusion of disabled people from the decision making process.

6. INVOLVEMENT OF PARENTS

Involvement of parents and relatives is another important dimension to examine if the organisations providing a service especially in the case of 'organisations for' take the views of service users seriously. The need to encourage and support parents and families with a child or adult with impairments is essential. None of the 'organisations of' disabled people provide organised support to parents. This could be largely because the members of these societies are adults and their programmes which are oriented to self-help cater for the needs of their own members. The focus of this analysis centres around 'organisations for' and

how parental involvement is encouraged and the mechanism provided to enhance involvement.

Questions can be raised with regard to the assumption that parental role is a good thing or even representative of disabled people. It is important to clarify that it is disabled people themselves who can best represent themselves. The role of parents can facilitate developments especially for people with learning difficulties. They may be a better representative in contrast to professional staff. Society for Families of Persons with Learning Difficulties is one such development in the Klang valley where family members are speaking up on behalf of disabled people and are breaking the charity framework. They are highlighting the lack of support services like day centres and neglect in educational and training opportunities. Furthermore providing appropriate counsel and support from within the social model of disability will enable parents and family members to become 'allies'. This will facilitate the move away from paternalistic care which characterises much of parental support.

Table 6 provides a useful summary and three indicators are used namely opportunities for electoral office, dialogue on programme planning and evaluation and finally the running of parents support groups.

Table 6 Involvement of Parents in ‘organisations for’.

	Number of organisations (N=21)	Number of parents
Holding elected office	10	49
Dialogue in planning and evaluation	6	127
Parents’ groups	11	276

6.1 Involvement in elected office

49 parents are involved in elected office in 10 voluntary organisations. It is striking to note that three organisations that do not run parents groups have parents represented at the highest level of decision making. Of the 10 organisations, the National Autistic Society of Malaysia has the largest number of parents in elected office ie 13 persons.

6.2 Dialogue sessions and input in planning and evaluation

Only 6 organisations organise regular dialogue sessions. A total of 127 parents were involved in this process.

6.3 Parents Support Groups

Only 11 out of 31 organisations in the Klang valley either directly run or work alongside a parents support group. Of these, a majority served people with learning difficulties. Two possible reasons for this are firstly, the age group of a majority of the service users is under 20 years of age. Secondly, in the case of people with learning difficulties those closest to them has been argued could also serve as their advocates in representing their needs, issues

and concerns. A total of 276 parents are involved in the various support groups in the Klang valley. Among the activities carried out regularly are: firstly, counselling sessions and mutual-support programmes, secondly, training workshops for parents on knowledge and skills in training their handicapped child/family member, thirdly, opportunities to discuss problems and issues, and fourthly feed back sessions on services provided.

The Society for Families of People with Learning Difficulties is the only parents' support group in the Klang valley region which is not a unit or group operating from within a service organisation. All other groups are specifically set up for parents and they do not have a separate legal framework to operate. This Society was set up by parents and one of their main objectives is "to act as an advocacy group and to raise public awareness". (SFPLD Constitution). Both Malaysian CARE and Dignity and Services are playing a significant role in the support and the development of this society.

Some disabled people as we will discuss in Chapter Seven and Eight have noted that their parents were a major hinderance to their empowerment, especially through their over protective nature or as in a majority of cases in Chapter Seven, abandoned their disabled children. It has already be cited that none of the 'organisations of' organise parents' groups. The emphasis of parents' groups centre around children with learning difficulties and service staff in 'organisations for' are playing a key role in facilitating these groups.

Foo (49) a parent of a teenager with learning difficulty affirms the role of parents. He said during an interview:

"I think parents, because they are the closest to their children, I think they are the best to understand the children's needs. So I think actually they should know better

what is suitable for the child.. No not that they don't love their child. Actually every parent loves their child very much. Some of them come and tell us 'don't know what to do with him'. That is the problem. No proper guidance, they don't know where to get the correct information, so we find that we [referring to SFPLD] can play a role in this "

Ping Lee (45), an interviewee is an executive staff in an 'organisation for' describes the complex reality facing Malaysian parents:

"I think one of the setbacks is that parents got no choice. First of all, there are no services available for them to place their children... Because of a lack of moral support and all that they have go through much difficulty where if a parent has got supports from a network of services as well as people who know about the work, then it would be felt as less of a burden, and they will have a more positive attitude towards the child".

The role played by Dignity and Services is to facilitate parents to develop positive attitudes and play a key role in advocacy of public policy and provisions to cater for the needs and rights of people with learning difficulties.

7. A TYPOLOGY OF VOLUNTARY ORGANISATIONS

It is necessary at this juncture to examine the underlying ethos or philosophical basis of the services carried out by and for disabled people. It is important to note that it is difficult to categorise the organisations and approaches into water-tight categories as there is overlap in the views, approaches and services provided by organisations. The approaches or models in this discussion are described as types. Furthermore some organisations incorporated more than one approach. Nevertheless the typology has some value in the comparative analysis of dominant approaches in the Klang valley.

The researcher started developing the framework by firstly examining the policy statements of the various organisations. 25 of the 31 organisations provided a copy of their stated

objectives. These were in the form of an extract from the constitution of the society or from their publicity write up. Only 11 out of the 31 organisations have a clear stand on disabled people which affirms their position in society, for equal opportunities and integration into society. Of these 4 are 'organisations of' and 7 'organisations for'. (See Table 7). With regard to a policy statement on involvement of disabled people in the running of the organisation (for example in holding office, in identification of needs, planning, allocation of resources and evaluation), only 4 indicated they have a policy. Of these 3 are 'organisations of'.

Table 7 Organisations and Policy Statements

	OF (N=10)	FOR (N=21)
Policy on disabled people and society	4	7
Policy on disabled people and involvement in the organisations	3	1

Voluntary organisations in the Klang valley have not developed a conceptual framework for practice which is well thought out and available in writing. This does not, mean, that there are no coherent thought patterns or values that influence the implementation of programmes for and by disabled people.

Oliver's (1984, 1990) five-fold typology of disability organisations provides a helpful starting point. This typology was developed taking into account the range and scope of the services in the context of the relationship to the State. Oliver (1984) notes that it is

not a rigid framework but a way of identifying distinct approaches. The five approaches (Oliver, 1990 : 117 and 118) are Partnership/patronage organisations which are 'organisations for' which are charitable; Economic/parliamentarian, also 'organisations for' but are single issue, parliamentary lobby groups; Consumerist/Self-help organisations which are 'organisations of' which seek to meet self-defined needs; Populist/activist organisations, also 'organisations of' which are political activist groups and finally umbrella/co-ordinating organisations of disabled people who are collective groupings rejecting clinical categories. This five-fold typology reflects the situation in the United Kingdom and is not completely transferable to the Malaysian context. However it can be adapted to the Malaysian situation and this is done a little later in this section.

Oliver did not develop the typology with a newly industrial country in mind, but basically to explain the situation in industrial countries. One major reason for the inability to transfer this typology to the Klang valley is because some of the approaches are not reflected in the Malaysian experience, while some are. For example approaches one and approach three are similar to the Malaysian experience and are adopted in the typology developed later. However approaches two, four and five are not developed in Malaysia. The single issue oriented lobby and research approach is just not present in Malaysia. Political activist groups of disabled people, do not exist in the Malaysian context, but disability activists do operate within the self-help movement rather than as a distinctive approach. In a similar way there is only one umbrella/co-ordinating organisation of disabled people which is MCD and it has only three national organisations as members. It has the potential to develop in the same way as its Western counterpart but at present it would be difficult to characterise it in the same way as Oliver does. MCD serves as the main avenue to communicate views

of disabled people to the relevant authorities and does not operate as a grass roots agency with local groups.

Darlington, Miller and Gwynne (1981) develop a four-fold model of care, namely warehouse, horticultural, enlightened guardian and disabled action. They build on the two models (warehouse and horticulture) developed by Miller and Gwynne (1972) ten years earlier in the study of residential centres for disabled people. Barnes (1990) applied the four models to day care centres for the physically handicapped. According to Darlington *et.al.* (1981), each of the models reflects a particular construct of disabled people. The first three are constructed by non-disabled people and the fourth is a construct of disability by disabled people themselves. 'Warehouse' implies that disabled people are 'less-than-whole persons'. It reflects disabled people's dependency on others. This is similar to the charity care model developed from the Klang valley study. 'Horticulture' on the other hand emphasises that disabled people are 'really normal'. In so doing the programmes organised seek to prepare disabled people for independence in a normal state like the able-bodied'. Barnes (1990) provides a clear illustration of this principle when he highlights two distinct avenues namely social rehabilitation (living skills training) and vocational/employment preparation. Barnes concludes that the philosophy that summarises this approach is self-determination. In many ways this is similar to the Klang valley typology of enabling care. Where it differs is that in Malaysia the professional sector is relatively underdeveloped and therefore the negative dimensions could be minimal. However the Malaysian experience highlights the attempts by some voluntary organisations to facilitate the involvement of disabled people in decision making processes at least in a limited way. In the case of 'enlightened guardianship' the emphasis is upon helping disabled people make a 'realistic

adjustment' to the able-bodied world. Barnes (1990) clarifies that in this model there is a combination of the assumptions of both the warehouse and horticulture models. Aspects of this could be seen in the enabling care approach in Malaysia. The final model developed by Darlington *et al.*(1981) is disabled action where disabled people are no longer passive recipients. This is similar to the self-help approach developed in the Klang valley where disabled people have set up and are organising the services which they feel are appropriate for their needs through democratically elected and accountable organisations.

In the models developed by Oliver (1984, 1990) he provides only two categories where 'organisations for' can be placed namely in the partnership and parliamentary models. However noting the models available in Darlington it is difficult to aggregate into just one model, as there are differences in the perception of disability, the strategy adopted as well as the outcomes. The typology adopted for the Klang valley provides more options for the current approaches in organisations which are dominated by non-disabled people. As the disabled people's movement is a recent development only one approach is provided namely, self help which is currently the dominant approach. However, Darlington is limited in the models available to capture the diversity within the disability movement which Oliver (1990) captures. Oliver provides self-help, activist as well as co-ordinating models. In the Klang valley there are indications of movements towards these developments from among the self-help groups. However for the moment all the 'organisations of' take a multi dimensional approach and therefore it is difficult to label them beyond the self help label. As indicated the trends are there as there are increasingly joint seminars and awareness programmes organised by disabled people across the traditional categories of impairment.

It is doubtful however if a strong political activist approach will develop given the nature of the Malaysian political environment.

A four-fold classification (See Table 8) which reflects the Malaysian context is developed, namely the charity care approach, enabling care approach, the advocacy approach and the self-help approach.

Table 8 Typology of Organisations

	Custodial Care	Enabling Care	Advocacy	Self-Help
Orientation	Charity	Charity	Rights	Mutual aid , equal opportunities & rights
Theory of Disability	Individual model	Individual model	Social model	Social model
Social Work Task	Providing for individual needs of disabled people	Adjusting individuals towards independence and integration	Challenging disabling environment. Focus on national issues	Building leadership potential & self-determination Service & advocacy
Limitations of this approach	Disempowering approach which creates dependency	Does not move far enough to develop the leadership potential of disabled people	Could be counter productive as confrontation is not acceptable in Malaysian society	Could become inward looking , as there could be a failure to link micro issues to wider concerns

7.1 Charity care approach and organisations

These services are organised for disabled people and could have been motivated by humanitarian or religious concerns. The charity care element or the dimension of providing 'for the other' in a custodial way is high in a majority of the 'organisations for'. The charity approach basically disempowers disabled people and creates dependency. In the three organisations which provide residential services the level of care and compassionate environment is positive. However disabled people are perceived from an individual model of disability. There is a strong element of underestimating the full potential of the disabled person. The care provided is very protective and disabled people are obligated for life for the service provided.

7.2 Enabling Care approach and organisations.

The focus of attention in the charity care approach is upon the individual. We noted in Chapter Three how Oliver developed this concept to apply where the primary task of the staff or helper is to adjust the individual to the particular disabling condition (Oliver, 1983 : 15). This is done either through physical or psychological adjustment. The motivation as in the case of charity care is cultural, humanitarian or religious concerns. The services are mainly organised by well established and distinguished personalities in society.

The major difference between the enabling care approach and charity care that it acknowledges the potential of disabled people. These organisations are oriented to make an assessment of disabled people's individual needs, develop an appropriate programme and prepare the individual person for integration into society. Enabling care is a positive step further away from charity care towards self help and advocacy. However it does not go far

enough to enable disabled people to take leadership and ownership of the voluntary organisation. Due to this limitation, the full potential of disabled people is not achieved nor tapped. Enabling care organisations have the potential to foster self help as well as to develop advocacy. One clear example of an enabling organisation which is categorised in this study as self help is the YMCA self reliant centre which develops the leadership potential of deaf persons and facilitates the transition from recipients to service organisers.

For limited periods of time, or on specific issues, enabling care organisations have been directly involved in advocacy alongside organisations of disabled people. An example of this is the role played by Malaysian CARE in co-ordinating the drafting of the Equal Opportunities Memorandum in 1989 (Krishnan, *et.al.*, 1989). The recommendations were presented to the government when the National Development Policy was being prepared. Malaysian CARE has also played a key role in the formation of a self-help group of parents namely SFPLD. Malaysian CARE staff play a key background role in providing support so that the parents group can take leadership not only in self-help, but also advocacy.

7.3 Advocacy approach and organisation

This is the least developed of the four approaches. There is currently only one organisation namely Dignity and Services (DandS), which explicitly identifies itself as an advocacy movement on behalf and alongside people with learning difficulties. DandS work on the basis of the universal human rights standards through the formation of self-advocacy groups as well as the training of advocates who will work alongside people with learning difficulties.

Four other organisations identify advocacy or rights work as one of their objectives. Three of these are 'organisations of' and the other is the parents group. The advocacy approach fits within the social model of disability developed by Oliver (1983). This is because there is:

a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environments impose limitations upon certain groups or categories of people (Oliver, 1983 :15).

The focus here is upon a wider understanding of disability issues in the context of national development. While a number of organisations are involved in community action and public awareness programmes there is a lack of coordination and monitoring of this form of activity. This is because the organisations have many other activities. There is lack of a concerted effort in advocacy oriented programmes. The general lack of involvement in this dimension might be as a result of the wider political climate which is not conducive to grass roots people's action groups. The prevailing approach is one of seeking to change the structures from within and through personal relationships and persuasion rather than on the basis of rights and confrontation.

Ding (53) a disabled person and activist *in the interview commenting on seeking to change public policies* said:

"We can say, access we are fighting already, not so good as what they have done in overseas. Their accessibility is better than us; Yes, it is true, but we are doing it very slowly. It is coming up. So we have to do our part to persuade, to keep on persuade and persuade to get what you want. I mean, it is very slow but we will get it one day. And in fact, in Malaysia, I think we can work very well with the government".

The difficulties faced by SBM were described in Chapter Four. SBM started off as an advocacy group but the events surrounding the amendments of the Societies Act in 1982

on whether one is a friendly or political society affected the advocacy element in SBM. While one of the objectives clearly identifies advocacy as a key element, "to express the views of the blind to government and other bodies on matters affecting the blind", SBM today is basically a self help society with a strong social service agenda. Its limited involvement in advocacy now is through MCD. This is not just based on a change in the strategy adopted namely instead of addressing disability issues directly SBM now channels such efforts through MCD, but as highlighted by some of SBM's founding members is a conceptual change in the organisation. This implies that SBM seeks itself as a service rather than advocacy movement.

7.4 Self-help approach and organisations

The self-help approach is basically mutual-support by disabled people themselves. They are self motivated disabled people who take the initiative and leadership in developing programmes for their own benefit. Mutual-aid and self-determination are foundational to this approach as well as collective action. All the 10 'organisations of' are self-help groups. Three other organisations that are included in this approach are the YMCA self-reliant centre, the SFPLD and the Gombak Community based rehabilitation programme. Therefore two fifths (13 out of 31) of organisations are self help groups in the Klang valley. The YMCA self-reliant centre is included in this category because their programmes enable self-help and leadership development at the grass-roots level. The SFPLD is also a self-help group of parents and family members of people with learning difficulties. Likewise the Gombak Community Based Rehabilitation where the leadership is by parents. The element which is common in all these 13 organisations is the aspect of group solidarity and collective action by affected people themselves. However the self-help group of parents and

family members is not categorised as an 'organisation of' as they do not have the required number of disabled people in the membership and elected office.

A self-help organisation:

may be characterized by self-determination and control by disabled persons, self-advocacy and mutual support mechanisms, aimed at strengthening the participation of people with disabilities in community life. (UN, 1991 : 12).

Self help organisations are closer to advocacy in contrast to enabling organisations. Almost two thirds (8 out of 13) of self-help organisations are involved in community action as compared to 4 out of 14 of the enabling care organisations.

POCAM, identifies its key priority as one "to help disabled members to become independent and self-supporting" (Leaflet). This is largely done through case work and in 1991/1992 the society handled 420 individual cases under three categories namely employment and training, orthopaedic and mobility aids and general welfare. While this is the major focus of POCAM it is also committed to advocacy and this is done through the MCD. POCAM's objective on this aspect is clear

to make recommendations to the government, and to advocate and promote laws, amendments to laws and other governmental regulations in the interest of the Orthopaedically handicapped.(POCAM, Constitution)

One danger that these organisations need to remember is the tendency to become inward looking and lose sight of the wider societal issues which affect disabled people in the wider Malaysian society.

8. Chapter Conclusion

In this study we have noted that voluntary organisations play a crucial role in the Klang valley in providing direct services to disabled people. Kramer (1981) in his comparative study of voluntary organisations in welfare states analyses the possible balance in service provision between the government, voluntary and private sector. From our study in Chapter Four and in this chapter we can note that in Malaysia the voluntary sector plays a leading role. Voluntary agencies play the pioneering role especially in some of the services to disabled people in the Klang valley because the State does not provide it. One could say that the Malaysia model is one where the voluntary sector provides the major role and the government sector complements and supplements it.

The voluntary sector is dominated by non-disabled people. While the political climate discourages critical political participation in society, active involvement in fostering a caring society and culture is greatly appreciated and recognised. This situation provides disabled people with opportunities and challenges in providing clear directions as to how the services should be organised from disabled people's perspective. There is a clear development of organisations set up and run by disabled people which are very active and well organised. There are times when there is cooperation among 'organisations of' and 'organisations for' . The presence of self-help groups is setting a new agenda for the empowerment of disabled people in the Malaysian context. In many ways the priorities set up by disabled people differ from those of non-disabled people as highlighted earlier in the chapter. This is reflected in the services provided, their organisation and management. However at the same time in a situation where non-disabled people dominate, sometimes the agenda of organisations of disabled people is likewise influenced by non- disabled

people. This is so in the case of SBM seeking to follow the same model of service as MAB to the objection of some of the founding members of SBM. Nonetheless the Malaysian experience provides disabled people ample opportunities to develop their own models and set the agenda for change.

One clear indicator of the Citizenship model of social work practice is the direct role played by disabled people in the decision making process. This indicator marks the difference from being active or passive. Ahmad's vision clearly reaffirms this theme. He said:

"What I want...is an 'organisation for' is more members in this organisation to be held by disabled people so that they all can be active in committees and to chair in committees so that the policies and decisions they created will be more by disabled people, that is more disabled voice. Disabled people who are capable, who are good, who are in a good financial status to come over and be members".

Chapter Seven, Eight and Nine further explore the nature of social work practice and organisational set-up by specifically looking at two service organisations, one an 'organisation of' and another an 'organisation for', representative of the different models. This is done to further explore the relevance and applicability of the citizenship model of social work practice in Malaysia.

DISABLED PEOPLE, CHARITY AND ENABLING CARE

1. Chapter Introduction

We have established in the previous chapter that the voluntary sector is a key provider of social services for disabled people. Through the macro study of the Klang valley four approaches namely charity care, enabling care, advocacy and self help, were outlined as being dominant in practice. In this chapter we will narrow our focus to critically review two of these approaches through the in depth study of one voluntary organisation. Earlier in Chapter Six it was noted that it was difficult to associate the approaches with specific organisations as they are not water-tight categories and that in most cases within an organisation there is an overlap of approaches.

Chapter Seven is an in depth study of one of the thirty one voluntary organisations in the Klang valley, namely an *'organisation for'* in which the dominant approaches were charity care and enabling care. As indicated in Chapter Six there are possible overlaps between the charity and enabling care approaches and this is discussed in the conclusion of this chapter. The overview of the organisation provides the necessary background information, after which six matters which emerged from participant observation and interaction with disabled people during the field study are critically reviewed.

On the principle of confidentiality the name of the organisation is withheld and it will be referred to in this thesis as Charity Care Organisation (CCO), likewise names of those interviewed are pseudonyms.

2. ORGANISATIONAL DATA

2.1 Historical and Structural information

As in the case of other organisations in the charity and enabling care approach, the initiative in setting up of the organisation is taken by well placed individuals in society with minimal or no participation or consultation with disabled people. This aspect was earlier described in Chapter Six.

In the case of CCO the setting up was initiated by an expatriate who sought the support of other well placed Malaysians and with the support of professionals from a leading hospital and the Department of Social Welfare. A member of the royal family agreed to be the Patron and a wife of a cabinet minister served as the first Chairperson. By December 1963 a residential home was established for twelve residents on land leased by the government.

However it was formally registered with the Registrar of Societies by October 13, 1970 as a society for charitable purposes only. According to the Constitution of the newly founded society four of the six objectives reveal the nature of the home namely :-

- to establish and maintain a home or homes for residents;
- to provide for the maintenance and welfare of residents;
- to provide facilities to enable residents to engage in fruitful activities and to become useful or fitted for employment by suitable care and training;
- to promote, organise, arrange and participate in conferences, meetings and lectures and subjects relating to the problems of the disabled and the chronic sick.

The constitution provides for open membership under five categories namely, Ordinary member, Life member, Institutional member, Associate member and Honorary member. For all legal purposes CCO is a locally constituted charitable society whose office bearers are

persons of Malaysian citizenship. The society is formally associated with three other programmes around the country under the umbrella of a National Council. Its links with the International body are informal, in fellowship with 250 similar programmes in 50 countries throughout the world.

The Society is managed by an elected Council of fifteen members. They all serve in an honorary capacity under the leadership of a President. The current president is the wife of a Cabinet Minister of the Malaysian government. It meets regularly to make all the major decisions of the society. The Selangor State Director for Social Welfare and the district social welfare officer are ex-officio. members. There are no disabled people who are members of the Society or the Council.

The implementation of the decisions is delegated to five sub-committees under the leadership of a Council member who serves as a Chairperson. They are House and Welfare Committee; Donations and Appeals Committee; Health and Admissions Committee; Residents Disciplinary Committee and the Building Committee. In actuality the most active committee is the House and Welfare Committee which meets monthly and receives reports from the Donations and Appeals Committee, and the Occupational Therapy workshop, as well as Health and Admissions committee.

The Hon. Secretary operates in an honorary executive position and ensures the implementation of all the decisions as well as drawing up matters for the Council and sub-committees attention. In other organisations of this size this role is played by a full time staff position as Executive Director or executive secretary. By International standards there

should be the Head of the Home (over all administrative head) and the Head of Care (over all the service dimension of the programme reporting to the Head of the Home) which are both staff positions. At CCO neither of these positions is filled. The Hon. Secretary oversees the total work especially the administration and fundraising. On the aspect of care, a senior nurse assumes the role and reports directly to the Hon. Secretary.

Services are implemented by employed staff (20 full time and 4 part-time) headed by a qualified nurse who is retired from the government hospital. The staff team is divided into administrative staff, nursing and care staff, physiotherapy and community staff and general workers. There is no disabled person in the staff team nor are there any who serve as volunteers at the Home.

2.2 Target Service Users

The major client group served are the physically handicapped. A majority of them are under forty years of age and they come from all the three major races in Malaysia.

According to CCO constitution the services are open to

men, women and children of all classes and communities regardless of religion who are chronically ill or permanently disabled and who are without any means or resources or are of limited means and resources. (CCO Constitution).

There are a total of forty-four residents and a majority of them are from the Chinese ethnic community (64%) as compared to Indians 23% and Malays 11%. It is uncertain why there is a higher number of Chinese as this does not reflect the general population.

Wong Poh Wan (1993:78) in her study of three Early Intervention Programmes for children with learning difficulties also noted a higher proportion of Chinese service users in

comparison to the national population distribution. She noted 35% Malays, 58% Chinese and 7% Indians. Jayasooria (1995a) in a study of nineteen voluntary organisations in the State of Selangor noted that 46% of the service users were Malaysians of Chinese ethnic origin, whereas Indians were 32% and Malays 22%. Two possible explanations are, firstly, the voluntary sector in Malaysia is largely catering for the non-Malay communities as often the Malay community would turn to the government agencies for assistance. This thought is conferred by Philip Eldridge (1991). He notes that:

Malays have learned to look to politicians and state structures for provision of services, making them less willing to form their own grassroots organisations or undertaking self-reliant initiatives. (Eldridge, 1991:4).

Secondly, the Malay community culturally provides for the disabled member within the family unit and would not be happy to isolate them in an institutional setting.

Table 9 CCO Residents - Breakdown by age, gender and race

AGE	MALAYS		CHINESE		INDIANS		OTHERS	
	M	F	M	F	M	F	M	F
21 - 39	1	3	5	8	2	2	1	-
40 - 59	-	-	6	6	2	3	-	-
60 and above	-	1	1	2	1	-		
Total	5		28		11		1	

Malays=11% Chinese=64% Indians=23%

2.3 Services Provided

The main service provided by CCO is residential services. It is important to note that the CCO Constitution, draws a distinction between a home and an institution namely "to be run as far as possible on the lines of a Home and not an Institution". Forty three residents have 'live in' facilities with three main meals provided along with medical and care support. The home also organises social gatherings and outings for the residents with the assistance of volunteers.

According to the CCO brochure,

the home aims to provide the fullest life possible for its residents within a secure family environment of affection and encouragement. The emphasis is on all-round personal development rather than merely treating medical conditions. (CCO Brochure).

It is indicated that it is more than just a welfare home for the handicapped.

It is a place in which the residents can acquire a sense of belonging, and of ownership, by contributing in any way within their capabilities to its functioning and development; a place in which to gain confidence and develop independence and interests; a place of hopeful endeavour, and not of passive disinterest. (CCO Brochure).

In this context five needs are provided for as explained in the brochure, namely physical, psychological, social, occupational and recreational. In the physical dimension aids are provided to increase mobility and independence as well physiotherapy. A friendly home environment provides the psychological support. At the social level encouragement is provided for socially accepted behaviour. At the occupational level assistance is provided to acquire employment. Recreational interest is developed through music, games, sports and social interactions.

In addition to the residential services CCO has introduced a number of programmes to encourage, motivate and provide opportunities for its residents to be economically active. The emphasis is upon self-reliance. A majority of the 44 residents are involved in some form of economic activity. In some cases it is full time employment outside the home, for others it is self employment (sale of lottery tickets, and other items like packet drinks etc.) For a large number it is full time or part time employment in sheltered work programmes in Thrift Shop, Handicraft workshop, contracted work at another 'organisation for' or at the CCO.

These work opportunities not only bring in the additional cash needed for personal expenses, they also provide funds for the residents to make a contribution towards their stay at the home as all working residents contribute 20% of their income to CCO. Most of all it enhances their personal sense of self worth and dignity, that they too can earn a living and make a contribution towards the cost of their stay at CCO.

2.4 Finance

About 60% of the funds are raised from the general public. The Department of Social Welfare, provide a grant which amounts to 15% of the annual budget. About 12% of the income comes from contributions by residents and their families. The remaining 13% is raised by sale of handicraft and other items.

Table 10 CCO Income and Expenditure Figures

Year	Income	Expenditure	Govt. Grant
1991	RM\$ 425,229.00	RM\$ 302,108.00	RM\$ 44,129.00
1992	774,390.00	689,471.00	31,317.00
1993	630,747.00	331,693.00	43,934.00

3. CRITICAL ISSUES IN CHARITY CARE

In the course of the field visits as participant observer, involvement among the disabled people, staff and Council members, as well as through the interviews (formal and informal) the researcher made six major observations. These emerged through unstructured discussions with disabled people, staff and Council members. While the findings have particular relevance to the organisation under study, it nonetheless has wider application in general to charity and enabling care oriented voluntary organisations. These aspects will be discussed in the chapter conclusion of this Chapter and later in Chapter Nine.

3.1 Residential care - a Medical Orientation

The home started off with the objective of providing residential services not with an institutional atmosphere but a *home environment*. The emphasis of the founders was in providing a place to stay which is home and it is for life. In many ways the model of the home is a transplant of the model from the United Kingdom. While CCO is an independently registered society in Malaysia nonetheless the conceptual framework was the UK model. Therefore some of the struggles of residents (Hunt, 1966, 1981) of similar programmes in UK have relevance for the Malaysian experience. Due to the cultural

difference the UK residents seem to be more aggressive in making their views known, while the Malaysian residents feel the same, they do not express it due to their vulnerable position.

Leading the protest was Paul Hunt (1966, 1981) who clearly articulated the stigmatization and isolation experienced by disabled people who were residents in an institutional set up.

He went on further to argue

that segregated residential institutions are essentially oppressive under modern conditions, and that they should therefore be phased out and replaced by secure, integrated living arrangements in which severely impaired people would be able to participate fully in society. (Hunt, 1981 : 1).

One must acknowledge the facilities at the CCO are good in comparison to other voluntary agencies and it is not isolated from the local community at least geographically as the CCO is located within the town area. However its structure and layout sets it apart due to the fenced up compound with the administrative block, main building, residents quarters and sheltered workshop area. There is therefore an isolating element within the community. It is not regarded as an institution because it caters for only 44 residents and considers itself a residential set up according to the CCO brochure.

Sally French (1994) makes an interesting observation in this context namely by stating that what an institution means:

has less to do with size than the style of management, the attitudes and behaviour of staff and the availability of resources (French, 1994:120).

She goes on to explain that

an institutionalized atmosphere can be created in a small group home, or even a family, just as a homely atmosphere can be created in a large institution, albeit with difficulty. (French, 1994:120)

Furthermore in practice CCO has adopted a medical orientation to social work practice.

This is reflected in three ways:-

Firstly, the most senior staff currently are two qualified nurses. Earlier the head of the home was called a matron and she too was a retired nurse. In the current context both the senior nurses are retired from government hospitals. They work on a shift basis with one of them on duty all the time. There is a provision of another part-time nurse who reports to work when the other two are on leave. In their staff structure the senior nurses are the most senior of the staff and the rest of the care staff report to them during their work shifts. In the interactions with these senior nursing staff one can gather their dedication to the work and their compassionate touch. The nurses are also the only qualified members of the staff team. While other team members have attended some courses they do not have any formal qualification. For a two year period the CCO has a physiotherapist from Japan. Physiotherapy also takes on a prominent dimension with the presence of this professional.

Secondly, at the House and Welfare Committee meetings one key aspect is the receiving of the medical report from the senior staff and the volunteer doctor who is a council member. While a number of reports are received namely administration, social, medical, remedial, physiotherapy, occupational therapy and residents disciplinary report, the medical report has a prominent place. This likewise plays an important focus at the Council meetings as well the Annual General Meeting. Different names are mentioned with details of their medical condition described. Over the past thirty years many of the residents who

have been long term in the Home are beginning to age and there are medical complications. In many cases these are part of the normal course of life, however for the home these are major concerns especially in sending the person for check-up and providing adequate medical attention. These are reported and discussed. A strong emphasis of nursing care is felt in the course of discussions and activities. Among the council members the profession that is closest to the work of the home among disabled people is the medical profession. The doctor council member who also is a founder member of the home, is very influential as she is the Chairperson of the Admissions committee. She said that she admitted every one of the residents and closely follows their medical condition. In one conversation with deep affection she said "I regard them as my children". This affection reveals both a matriarchal and patronising attitude.

Thirdly, The question of responsibility is linked to the medical notion. The Home now is responsible for the residents who have left their own homes and are in CCO's care. This thought builds up a strong paternalistic aspect of caring. The constant fear of the Council is to avoid any bad publicity of a lack of care. Therefore to be on the safe side utmost care is taken to ensure their good health. In the early stages of the researcher's visit one Council member highlighted the incapability of the residents to take adequate care of themselves because they were confined to a wheel chair. The impression given was that the 'inability to walk was the worst of the disabilities'.

It is without doubt that the medical profession has a strong control over the residents of CCO and their existence is conditioned by their medical wellbeing. Much is being written now by disabled people (French, 1994; Morris, 1993) on the construction of disability in

the interrelationship between dependence and independence in matters affecting day to day living. Non-disabled people tend to focus on the ability of disabled people to cope on their own therefore there is emphasis on living skills training (bathing, dressing, self care). Morris (1993) explains that the vulnerable position disabled people are in is that the need for personal assistance is seen as involving dependence on the carer. The perception here is that autonomy and independence is seen in the ability to do things for one's self. However disabled people are challenging this perception. To them it is not the ability or non ability but the use of control over the personal and other services. In their writings disabled people have expressed that they do not mind others doing things for them but the issue is, who is in charge.

Disabled people define independence, not in physical terms, but in terms of control. People who are almost totally dependent on others, in a physical sense, can still have independence of thought and action, enabling them to take full and active charge of their lives (French, 1994 : 49).

In the case of CCO residents it is a situation of powerless in the presence of a dominant medical perspective which conditions their outlook and experience.

As a possible first step away from the individualised and medical focus, Council members and senior staff should be introduced to the developments of independent living schemes in other CCO programmes. This orientation will widen the current perspectives of Council members and foster greater positive images of assisting disabled people. CCO could draw valuable lessons from a programme in Toronto.

It consists simply of a number of separate, accessible living units which have been integrated into an ordinary apartment building. (Cheshire Smile, 1994 : 22).

At CCO there is one couple (both disabled) living in a separate unit. They got married in the home. One suggestion made by a Council member in an informal discussion with the researcher is the possibility of building more one unit houses within the compound. It will be better than the rooms in a wing concept but it does not go far enough to integrate disabled people into the local community nor give them the opportunities for control over the lives. For none of the residents is living out a possibility as they do not have the financial means to rent premises or employ personal assistants. Neither do they have family members who will be willing to assist them. This is one major difficulty with the voluntary sector namely that free will contributions are made to the organisation and not to disabled people directly. While the funds are raised in the name of disabled people they have no decision making power on how it should best be utilized.

3.2 Residents' involvement

Residents are not involved in the main decision making processes of the Council or its Sub Committees. While there is a provision for honorary members namely members with voting rights but who do not need to pay an annual subscription, none of the residents are members of the CCO. In fact a majority of the Council members are well placed, affluent members of Malaysian society. This is a reflection of charitable work in Malaysian society where the rich and affluent give sometime for charitable work which give them a lot of publicity in the media. In the interaction with Council members one gathers their lack of exposure to the contemporary changes in social work practice among disabled people both at the international and the national level in general, let alone the changes that have taken place in similar programmes elsewhere, not least in the international agency CCO is associated with in the United Kingdom.

What surprised the researcher was their lack of knowledge of the developments at the international level with regard to the Charter¹ on user involvement and independent living centres in projects around the globe. This is because a copy of the charter hangs in the conference room and an international newsletter containing the charter and examples of independent living was circulated to all the council members by the Secretary of the council. This charter sets out the beliefs, principles and future aim in greater detail than ever before. It builds upon the existing mission statement. It is hoped that this charter will do two things. Firstly, it identifies the main policy challenges likely to face the organisation over the next ten years. Secondly, it sets the framework for review of the internal decision making and management process. Among the five aims one is most timely, namely, that people with disabilities will be offered "the opportunity to take an effective part at every level in the running our services". The Charter is yet to be publicised to the residents. Council members have not realised the full implications of this for the way services are carried out currently. They carry out their duties as they have in the past. There is therefore an urgent need for Council to study the Charter, adopt it in Malaysia and chart out a plan of action to implement it.

There is only one formal gathering where residents can give feedback to the Council. It is the Residents' Disciplinary Committee which is chaired by one of the Council members. It is scheduled to be held monthly, however between August and December 1994 only one meeting was held. Residents are provided an opportunity to share any problems they have in the home. For example residents raised common problems like household matters such

¹This Charter was developed by an international organisation with which the CCO is associated. A reference is not provided as this will disclose the identity of the CCO.

as repair of bathing chairs and doors and even personal matters like false teeth or spectacles needed by residents. It also provides an opportunity for the Council to make some formal announcements.

However this forum is not effective as one resident said "it is a time for them to talk and we to listen". An overseas student volunteer who was attached to the home for six months highlighted the problem to the researcher:

"The Council member stands in front of all the residents and asks 'are there any problems?'. In such a situation no one will speak, other than say the routine, it's OK. Residents are afraid to say what they really feel, because of stepping out of line. As well as afraid they will be asked to leave. They have their views but keep it within them".

Guan (40) one of the residents interviewed was frank about this matter. He said:

"There is problems but don't bring out. Sometimes takut [afraid] to bring out our problems. You taking too much, you are a bad person, too much complains. Budak jahat [bad boy], not grateful for what they have done. Must keep quiet".

Guan (40) went to affirm the positive concerning the home. This is a constant tension among a number of the residents to hold a balance between saying positive and negative aspects concerning the home. He said:

"I love this home. I now think it as my own home. They are good to me - the care staff, committee members".

He however went on to raise his main concern with the home especially with regards to the new building and the residents not being consulted on this matter. He said:

"The home must be accessible. Disappointed with the new building. Rams should not be high. Did not know the road will be raised. Difficult for me, my hands not strong. Don't know the plans. Quite important to make all things suitable, if not then others will have to help us. So far no one asked, they [referring to the Council] did not ask us about the building. If asked will tell. Did not tell how I feel".

Fatimah (31), another resident interviewed, commented on the matter of the new building and the issue of access and the lack of consultation on these matters. She said:

"we think about this in our heart. Even if we tell, no one will listen to us. Don't make longkang-longkang [drains], now there is so much. Need to make everything smooth, no slope and everything should be on the same level. Now some are high and others are low. I don't tell. If you do they think we are against. They say, ' we know what's best for you all'. Because of this I don't bother. Here we have no choice, we can't tell. If I tell, will get into big trouble. What they do is up to them. With the previous Matron she told us, if you don't like it here you can leave. We expressed our unhappiness, no one on our side to listen. Council believe the Matron".

The Matron left in the middle of 1993 and since then the post is still vacant. Meena (25) indicated that if she has a problem she too does not bring it out, "cry over it. If someone ask then I will say what is the problem". However Glory (40) said that if she has a suggestion or problem "I tell. If I am not happy I will tell".

With regard to the residents' meeting, one point to consider is the very name of this committee, which reflects an unbalanced approach to the relationship between the Council and the residents. In one meeting the Council member chairing stated that he, "was pleased with the residents support towards the Home by behaving very well" (Minutes : April 2, 1994). Whether residents are disciplined or well behaved was discussed in all three House and Welfare Committee meetings attended by the researcher. In one meeting reference was made to one resident, namely, he "does not follow the proper procedure in spite of repeated warnings" (Minutes : August 2, 1994). In another meeting reference was made to how the residents took advantage of the two overseas volunteers. The committee decided that they must be told not to do the chores of the residents unnecessarily (Minutes : Nov.15, 1994).

This basically is from the perspective of the council members or staff. In many ways it is difficult for a resident to openly share difficulties² in this area as they are not co equals even with staff. They are there at CCO on the "good will" of charity and not by right. At all the major policy and decision making meetings the residents are not represented and they do not really have a voice. What's more they have no real opportunity other than the only formal channel available, the Residents' Disciplinary Committee.

In line with the user Charter a plan of action needs to be developed. This could be developed over a period of time by firstly inviting members of self-help groups of disabled people to run an orientation workshop for CCO membership and Council. A radical change at this level is essential where non-disabled people will have to learn to give up power and play a supportive role.

Secondly, it will be necessary to open the membership to all the residents and they be elected into different sub committees and the council itself. This will result in the reorganising of the various committees and the change of the name of these committees. In the first instance the name of the Residents Disciplinary Committee must be change to a more positive one.

It is doubtful if the CCO members will make such a drastic change and therefore an intermediate phase is for residents to be represented in the various sub committees. Some

² The residents' openness to the researcher could be explained. Firstly, the researcher hold no executive or administrative powers, therefore they do not have to fear the researcher. Secondly they expect the researcher not to reveal, who among them have specifically said what. This is a possible reason for a majority of the residents to refuse the interviews to be tape recorded.

of the sub committee roles could be delegated to disabled people for example the coordination of supportive care staff (personal assistance) as well as the running of the kitchen.

These measures will be meaningless without a clear commitment to user involvement. This has to be done in stages for "tokenism" is not really empowerment as indicated by Peter McDonald. According to him:

we need to put a lot more thought and effort into the process of empowering people. It is not enough simply to add a disabled person onto a Committee- we need to ensure that we are using their skills and experience effectively. To this end, we must look at more imaginative ways of gaining the opinions of our residents and clients. (McDonald, 1994: 11).

3.3 Employment related issues

While the main emphasis at CCO is residential care, the second major focus is assisting disabled people in employment related matters. The orientation is to ensure that disabled people have some work skills. Opportunities are provided in sheltered workshops, open employment or in self employment. However, there is little co-ordination of this activity and much more needs to be done to strengthen this dimension at CCO.

Firstly, among the staff team no one has the responsibility to look into employment issues and matters pertaining to disabled people. As indicated earlier the major focus of the staff team is towards nursing care and meeting of other basic needs for example food and home maintenance. Ahmad, over a three month period, faced problems at the work place. He shared his difficulties with a number of people among the staff team as well as with visitors, however no action was taken. The nurse in charge told the researcher "he is a

sickly boy, maybe he does not need to go to work". The possible indication is that he is giving an excuse for not wanting to go to work. However Ahmad a new comer to the home is a very determined person. It is he who told the researcher "we too can work, we are not just staying here doing nothing". The Home environment and the security it provides for example food, shelter and nursing care, can de-motivate residents to face the harsh realities of the world outside the compound. Work progress is not monitored like health care of the residents. For example no report on employment is presented at the Council or House and Welfare Committee meeting. The impression one gets is 'as long as they are busy doing something and earning a little, it is good enough'.

Employment of a member of staff to co ordinate and support the residents will further enhance the capacities of the residents, as well as create new opportunities. This person could serve as a placement officer. This service could be extended to other physically disabled people living in the community surrounding CCO as well.

Secondly, while there is a sub-committee on Occupational Therapy their report tends to focus on the sale of handicraft items produced. The general quality of the hand work at the handicraft workshop is high and their sale turn over is good. Volunteers as well as council members provide assistance in the improvement of design, display and sale. Within the current structure this sub committee could develop a comprehensive reporting and monitoring mechanism to enhance the work experience of the residents.

Thirdly, with the assistance of the researcher the September 1994 newsletter described the work experience of the residents as two articles focused attention on the residents'

involvement in income generating activities. As indicated earlier the Home encourages residents to be either self employed, or employed in a sheltered workshop or employment in the open market. There is however a need for greater co ordination of the activity. One of the residents interviewed expressed his determination to be independent. Foo (37) said:

"If residents wish to go out and work they can. Usually I am out by 6.30am., and do not return until past 12noon. I prefer to work and earn, so money is valuable. Life-no meaning, if you are not doing anything".

He sells lottery tickets in a market which he has been doing for the past fourteen years. He takes a lot of pride in his work and finds that it makes his life interesting.

Fourthly, no analysis or evaluation has been made of the sheltered workshops to assess if the residents are making progress in their work and more so the level of income earned. Most urgent of all is to question whether this is what disabled people want to do. Glory (40), another resident interviewed said concerning work at the sheltered workshop. She said:

"No future-lah. Even my supervisor says that, try and find another job. Have never tried another job. Don't know what is suitable. Current work is OK but salary not enough".

Two others interviewed, Fatimah (31) and Ahmad (24) who also worked at the sheltered workshop have managed to leave it for open employment in a factory. They too commented that the pay was low, the same year in and year out.

In the charity care approach the priority is given to custodial care. CCO's understanding of work among disabled people is doing what it feels best in the interest of disabled people who are in their care. The emphasis in the enabling care approach is seeking to prepare

disabled people for self reliance not only in personal living skills but also to acquire some work skills. In due time it is hoped that they will be financially independent to support themselves and thereby regain their sense of dignity and independence. CCO is making a move towards the enabling care aspect with the new focus on employment related matters.

3.4 Special meals

Between September and December 1994 there were forty-three special meals for the residents. These included outsiders hosting the residents at the CCO for tea, lunches or dinners, as well as visits from VIPs to present cheques to the Home or presents to the residents. While these gatherings are times of fun and enjoyment, they have a lasting impact upon the residents in a number of ways.

Firstly, these gatherings benefit the givers more than those who receive. All the residents are above the age of twenty with a large number above thirty, these occasions make them feel like children who are helpless, needing the charity of the general public. Food, fruits and cakes are often the way of cheering up these unfortunate residents. For the givers it is a time of playing their part in caring for disabled people. It is short term support. In most cases it's just a meal for some presents. The visitors overriding perception is that disabled people are helpless, rejected by their families and community.

Secondly, the constant flow of visitors disrupts the normal course of life for the residents. However for a majority this has become a way of life. Waiting for gifts and food from well wishers could be seen as their profession. For a number there is a feeling of wanting to receive as a result of the 'hand out approach'. Some are under motivated and sitting around

in their wheel chairs, looking and feeling miserable. The atmosphere of forty four disabled people in a small compound provides an artificial environment surrounded by an unfriendly community which erects barriers between itself and disabled people.

Thirdly at these social gatherings all the disabled people are in their places ready to receive their portion of what is provided. The visitors mix and chat with them. The residents are passive. As one observing the scene, one can equate this scene with the notion of "show pieces" of human charity similar to visiting a Zoo of animals. The movement of people is so fluid that it is difficult to build meaningful relationships. The residents would like to have friends who are prepared to foster lasting relationships and friendships. Ahmad (24) expressed in vernacular Malay:

"when I first came, found it a problem. I come from Kampong, the food, others here. Now OK. Boring sometimes, no friends. Parties OK [referring to these gatherings] if Chinese food, not used to their food. But Indian I'm ok. Not a big problem. Often I'm shy. Not used to it. I give thanks to God. People remember us. If the people I'm not used too I feel shy".

Fatimah (31) commented "no problem with food but not all [referring to the visitors] are friendly. Glory (40) commented that:

"I like to make friends. Visitors sometimes don't talk, we too don't talk. Scared, not sure if they like it or not - the way people look at us, strangers afraid to talk".

On discussing this matter with the thirteen interviewed all of them said that they had no problems with the gatherings for special meals. In fact many enjoyed the food and the company of the visitors. John (32) a resident and one interviewed, indicated that it was beneficial especially for those who do not go out of the compound and help to prevent isolation. Another, Gopal (46), indicated that it assisted the home in fundraising as those who came would also contribute funds to the home. A number wanted to make suggestions

for the menu as well as wanting the visitors to be more friendly and to chat with them. However the cultural feelings of appreciation were strong as reflected in Kiong's (45) comment during the interview:

"we cannot say [indicating negative comments), i t is bad to say anything against because they come to give us food. Staff and Council will be unhappy. ' Why do charity? You are ungrateful'".

Another Muthu (42) said "if we feel we are fed up, we can't do anything". Guan (40) indicated that:

"residents should not be choosy. If someone gives a treat, eat, say thank's a lot. If you can't eat keep quiet".

At other times visitors take the residents out shopping and on outings. Chee (28) expressed her preference to be taken out for an outing more than food. During the interview she said:

"Take us out we will get to know them more. Go shopping and cinemas. Many just give food, but don't talk and they say bye bye. Every time mayan-mayan(food), feel bad to tell them what I really feel".

There is a strongly felt need among residents to go out. At the September 10, 1994 residents meeting the residents requested for outings and picnics. They were promised that when the new bus arrives this will be organised. This is where if visitors established closer ties and if they truly wanted to respond to the needs of the residents they would enquire what they want and would like to do. Very often visitors bring food stuffs which the residents cannot finish and at times it all goes to waste or is distributed to other centres.

3.5 Mindset Issues

Conceptual development and exposure to disability issues is lacking as the residents do not interact with other disabled people in self-help groups although a number are members of

self-help groups of disabled people. One possible factor could be an inferior feeling as a result of a lack of education as well as being confined to a home. A majority of the disabled people in self-help groups have a stable job and live in their own homes. The highest level attained by a resident in CCO is GCE 'O' levels, and a majority have no formal education and are working in sheltered workshops. The other factor could be transportation problems as only two of the forty-four own their own transport in the form of motor-cycles with a side car.

At the current stage residents have a certain freedom with regard to their time. They are free to go in and out of the Home but need to write in the record book if they are staying out overnight. They have to come for meals on time, but can inform if they are likely to be late and their meal is kept for them. A number of the residents eat regularly outside. They are free to take a job outside the home or in a sheltered workshop. They have the liberty to chart out their own activities. However even within this liberty some feel morally trapped to fulfil what is expected rather than their personal choice. Lisa (35) shared with sadness in her heart. She had a better paying job outside but because more hands were needed to work in the sheltered workshop she agreed. However the pay difference is great according to her. She would earn more outside then within the sheltered workshop. Lisa said in vernacular Malay:

"I am happy to stay here. In kampong [village] no friends, no one. Not very happy with job here. I told Puan [Mrs, referring to council member]. Three months I get RM100.00 then deduct RM30.00 so I get only RM70.00. What to do. I must work to pay my stay. They want me to work here. Also if work outside, problem transport. But I really prefer to work outside".

One major aspect that is crucial is the institutionalization process and isolation from mainstream society experienced by a majority of the residents. Of the thirteen interviewed

70% have been in the home for more than ten years. 40% have been in the home for more than 20 years. Institutionalization takes time to seep into the mindset and once entrenched it is difficult to change the mindset. A number of examples can be cited from interaction with residents. Muthu (42) has been in the home for 28 years since he was first admitted at the age of 14. He said that in the beginning he wanted to have his own home. He said:

"Really dreaming but now my heart don't like anything. Tried to get home, went to Dato... and Mr ... [both politicians, the first a Minister with the Malaysian government and the second a leader in the opposition and trade union] but nothing. Heart wants but it's late. Can't manage by myself. This home everything I got".

With Foo (37) it is a similar story. He came to the home at the age of 10 and has been here for the past 27 years. At one point in 1985 he caused great concern over his problem behaviour at the home. The clinical psychologist who made an assessment of him wrote that

He [referring to Foo] seems to have idealized the world outside the home of which he seems to know very little, and to see the community of the home as a hostile and unfair environment. (Assessment report).

Ten years later in the researcher's interview with him, he described life outside the Home as "...very difficult and hectic. Want to stay here, outside life is boring and I don't like it". What has happened to both Muthu (42) and Foo (37) is the experience of becoming institutionalised .

Shakespeare (1993) acknowledges that disabled people as much as non-disabled people could be socialised to see disability as individual medical tragedy. He draws parallels with the 'false consciousness' in Marxist literature and 'internalised oppression' of Feminist writers. Shakespeare goes on further to note that in comparison with other socially oppressed groups people with impairments may find it more difficult because the

oppression is couched in terms of paternalistic support and charity''. (Shakespeare, 1993:256). French (1994) likewise echoes a similar analysis that disabled people can:

become internally oppressed by viewing themselves in the same way as non-disabled people view them, and behaving as others expect them to behave. (French, 1994:56).

For both Shakespeare and French the way out for disabled people is to adopt the alternative interpretations put forward by the disabled people's movement. However the residents of CCO are trapped within an institution which is hailed by the general Malaysian society as doing a good job.

The experience of isolation is real for the majority of the residents. Taking into account that only two of the forty-four residents have their own transport a majority of them spend a major portion of their time in the CCO compound. Their experience of isolation must be great. Their real contacts with the world other than the electronic media are those who visit them with food and gifts. These experiences reinforce feelings of dependency and helplessness building negative conceptions of their personal capabilities as well as a negative sense of pride and self-image.

3.6 Staff Related Matters

A majority of the twenty full time and four part-time staff do not have training related to disability work. The two senior staff are retired nurses. Six full time and three part-time staff serve as care assistants. They work closely with the two senior nurses and are responsible for attending to the care needs of residents such as feeding, bathing, putting to bed, getting residents ready for work or other duties. The majority serve as domestic workers namely cooks, gardeners, drivers, cleaners and they work on a shift system. Two

work in an administrative capacity in the Home office. The senior member of staff is the nurse on duty, who keeps a daily record book referred to as the nursing book in which they record key events or happenings of the day. Items recorded include the medical attention given to residents, hospital and clinic visits, complaints of residents or staff. The nurse in charge also updates the residents' personal files. From interaction with the staff and residents as well as from reading the personal resident files and the daily record book one can draw the following observations.

Firstly, while there are clearly good intentions in the hearts of all the staff there is clearly a lack of appropriate training and orientation for all staff concerned. The senior staff member is from a nursing background and does her job with dedication from that perspective and experience. There are no standing guidelines for the daily record or the updating of residents' files. In fact there is no proper annual assessment of residents or a comprehensive case history written annually. With regard to daily records it's basically left to the individual staff concerned. There is no real monitoring and follow up on what has been written. In the event of a problem or crisis the Council members may want to read the appropriate sections. What is written is basically, as indicated by the senior staff, "to cover themselves". The situation is most acute among the domestic level staff whose lack of exposure, awareness and training is hindering effective rehabilitation. None of the staff in this category are educated nor have they received any appropriate training in working with disabled people

French (1994) makes similar comments on the situation in the United Kingdom that staff in many residential settings are "often untrained, poorly educated and under paid" (French,

1994 : 122) She goes on to highlight the negative effects not only on staff but also on disabled people. This is because the staff level low expectations of the residents and this has a reciprocal effect upon disabled people who as French (1994:122) notes fulfils a 'self-fulfilling prophecy' by emulating the expectations of the staff.

Secondly, a number of residents have indicated their major difficulty with the domestic staff. Gopal (46) is very open about his frustration. About the home he said

"all is good only staff are not helpful. Not all but a few. Sometimes they scold when we ask what we need and they make my heart pain. This is my feeling. Now when we ask we are careful, afraid if they scold".

Glory (40) comments that the staff are not patient. During the interview she said:

"They [referring to staff] want very fast. We are quite slow people. Sometimes they scold. If they scold I cry. I have no right to scold back. I respect them. They don't respect me and they scold. Sometimes they treat us like children".

Many of the domestic staff have been long serving and have seen the disabled people grow from childhood. While CCO policy states that staff should not verbally or physically abuse the residents, in practice verbal abuse is common place and has tremendous psychological effects upon the self-worth of residents.

Jenny Morris (1993, 1993a) highlights the difficulties disabled people face in the use of personal assistance. As indicated earlier she argues that the issue for disabled people is the control element in the service provided. She goes on to note that most service providers expect the service users behaviour to be that of "undeserving, demanding supplicants" (1993a : 31). Jane Campbell (1993:53) refers to this as the "struggles for independence"

namely the control over the daily personal assistance needed in order to get up, go to bed, eat and get about. Morris affirms that:

user control in the delivery of services is a civil rights issue. We're not talking about an optional extra here. We are talking about something which is absolutely necessary if people are to live a reasonable quality of life. I go into people's homes and listen to stories which remind me of Terry Waite's description of what it's like to be a hostage. To be shut away, not listened to, your life devalued, and for some people to have no concept of how such a situation can ever end. (Morris, 1993a : 32).

4. Chapter Conclusion

The dominant aspect of the charity care approach is the caring dimension of service provision which takes a strong medical and individualised orientation, as well as creating dependency. In Chapter Two we noted how Oliver provided a critique of this inadequate understanding of disability. The enabling care dimension moves a step away from the caring and curing focus to enabling disabled people through rehabilitation to develop daily living and employment skills. The more progressive aspect will point beyond daily living to personal assistance and from sheltered workshops to open or self employment as indicated in Chapter Six.

Central to this discussion is the meaning of caring. Bulmer (1987) defines caring as helping, supporting and protecting vulnerable and dependent members of society. He goes on further to highlight three components of care namely physical tending which is the most intimate kind; material and psychological support which does not involve physical contact and finally generalized concern about the welfare of others. Dalley (1988) on the other hand makes a distinction between caring 'for', which is the tasking of tending another person with that of caring 'about' which is feeling for another. Morris (1993) builds upon these definitions to indicate that in the context of disabled people caring 'for' is understood

as "taking responsibility for... taking charge of" (Morris, 1993:149) rather than in the sense of caring 'about'. This Morris clarifies is linked with the notion of 'dependent people', where "they are assumed to depend on others to take responsibility for their well-being" (Morris, 1993 : 150). The independent living movement is challenging the assumption "that physical inability to perform daily living tasks inevitably creates dependency" (Morris, 1993:150). Morris (1993a) also explains that the central issue is one of control irrespective of whether the disabled person is in residential care or in the community. This control is not understood in a narrow sense of personal ability to do but in the sense of ability to be in control over how the assistance which is provided and the choices available. The primary aim "is to increase the quality of and people's control over their own lives" (Morris, 1993a : 33)

While the humanitarian concern to care for another is commendable, it must be done within the framework of caring 'about' rather than 'for' as in taking custodial control. It is essential to give serious consideration to the views expressed by disabled people as they define their needs and the ways they would like the services delivered. This principle must be applied whether it is services provided in a residential or community setting. Morris study (1993) highlights the similarity of the institutionalisation experienced by disabled people in either residential or community settings. Furthermore she reveals that while some disabled people felt that they were made:

dependent by residential care... others experienced residential care as giving them a freedom which they could not have when living in their parents' home. (Morris,1993 : 55).

This does not mean residential care is one option or choice for the better rather it is the reality which is currently available.

What is needed in the Malaysian context, are independent living units or group homes with the support network of personal assistance available under the control of disabled people themselves. Therefore the direct involvement of disabled people at the levels of identification of needs, making appropriate assessments as well as decision making in the allocation of resources is essential. In so doing 'organisations for' can make radical progress in setting a new agenda for social work practice alongside disabled people in Malaysia. This is at the heart of a citizenship model of social work practice.

DISABLED PEOPLE, ADVOCACY AND SELF HELP ORGANISATIONS

1. Chapter Introduction

Emerging out of the Klang valley study of voluntary organisations was a four-fold typology. We critically evaluated two of the approaches through the study of one 'organisation for' in Chapter Seven. In this chapter we will examine the two remaining approaches, namely, advocacy and self help through the study of an 'organisation of'.

What is emerging out of the field study is that there are major differences between 'organisations for' and 'organisation of'. A general survey of the differences was outlined in Chapter Six in the overview of the thirty-one organisations. However with a deeper and more critical analysis major differences in organisational structure, service priorities, approaches and services provided are identified. We will more closely analyse these in Chapter Nine. However the orientation of 'organisations for' towards charity and enabling care is evident, as the 'organisations of' are directed towards advocacy and self help.

Earlier in Chapter Four we noted the reference David Korten (1990, 1995) made concerning people's organisations which can be applied to an 'organisation of', *that they are the fourth sector*. Korten identifies three characteristics of people's organisations. (Korten, 1990: 100). Firstly, they must be mutual aid or benefit associations; secondly, they must have democratic structures and finally they must be self-reliant. As we make an in depth study of this organisation we will explore whether this organisation is reflective of these characteristics.

In this in depth study we will examine critical aspects of the advocacy and self help approaches in the light of Malaysian experience. As in the case of the CCO, this 'organisation of' disabled people will be referred to as a self-help organisation (SHO) and all the names of those interviewed are pseudonyms. While SHO is a national organisation, their services in the Klang valley are the focus of our attention in this Chapter. We will make an attempt to compare these with the western counter-parts in more industrialised countries. However the critical review of the fourfold typology in the light of the citizenship model of social work will be tackled in Chapter Nine.

2. ORGANISATIONAL DATA

2.1 Historical and Structural information

The inaugural meeting of the SHO was held on August 1975 and registration was formalised by the Registrar of Societies by September 1976. One factor which was central for the formation was, that while other disabled people such as the visually and hearing impaired were catered for by organisations, the interests of Orthopaedically disabled people who were more numerous had been neglected.

It was formed at the initiative of two men. One was a former highly placed civil servant who had acquired paraplegia as a result of poliomyelitis in young adulthood. The other, a person without disability, was recently retired from a series of senior positions in the government's rehabilitation service system. Together, the two men represented position and respect in the Malaysian disability/rehabilitation community, a wealth of experience and connections with government, strong links with leaders in most non-government domains, and a large amount of dedication to their cause. (Armstrong, 1993 : 188).

The Society's Constitution has eleven aims and objects, of these four are significant namely:-

- To find ways and means of improving the physical, social and economic conditions of the Orthopaedically handicapped

- To help in the education, training, employment and resettlement in society of the Orthopaedically handicapped
- To organise sporting, social and other events for the benefit of the Orthopaedically handicapped
- To make recommendations to the government, and to advocate and promote laws, amendments to laws and other government regulations in the interest of the Orthopaedically handicapped

SHO is a registered society under the Registrar of Societies. Its membership structure has four categories of members namely ordinary members, associate members, life members (either ordinary or associate) and honorary members. Ordinary membership is "confined to persons who are Orthopaedically handicapped" (Constitution : 3) whereas associate membership is "open to non-handicapped persons who desire to assist the Orthopaedically handicapped" (Constitution : 4).

This is the uniqueness of SHO, while it is set up and run by disabled people, they make provision for non-disabled people to be associated with them. Furthermore ordinary members who have voting rights can nominate and elect non-disabled people into the committee. Non-disabled persons who are associate members do not have voting or nominating rights. From the inception of SHO a partnership model developed with disabled people having the controlling interest and power and non disabled people served on the invitation of disabled people. There is a shift in the power base which is radically different from 'organisations for' disabled people most of which have not made specific provisions for the incorporation of disabled people in their organisations.

The Society is run by an elected committee chaired by a President, five officials and not more than nine and not less than five committee members. Elections are held once in two

years at the Annual General Meeting. There are four sub-committees namely Employment, Welfare, Sports and Aids/Medical. In addition there are three regional committees in the States of North Kelantan, Johore Baru and Penang Island.

SHO has two full time staff, an executive secretary and an office clerk, both of whom are disabled people and ordinary members of SHO. SHO has a sizeable number of regular volunteers about 70 to 100 in total at the National level, who assist in the implementation of the programmes. Furthermore, SHO has a member of the royal family who serves as its Patron as well as three leading Malaysians namely a lawyer, an orthopaedic surgeon and a former National director of sports to serve as advisors. All of them are non-disabled people and they play a supportive and advisory role in their professional capacities. From time to time their services are called upon especially in providing introductions for the benefit of the members. Here is an effective way where disabled people have involved non-disabled people on their terms to play a part as 'allies' for the enhancement of the movement.

SHO networks closely with other agencies. It is a member of the Malaysian Council for Rehabilitation (MCR) which is a coordinating committee of organisations working 'for' and 'of' disabled people. SHO is a founder member with other national bodies of disabled people of Malaysian Confederation of the Disabled (MCD).

2.2 Target Group Served

The total membership of SHO at December 1994 was 920 ordinary members and 66 associate members at the national level. SHO has members, who are all adults, in every

state of Malaysia. A majority of the members are self-employed and the current unemployment rate is only about 5%. It is however noted that a large number could fall under the underemployed category. In the Klang valley there were 369 ordinary and 33 associate members at the end of December 1994.

Table 11 : SHO Klang Valley members by age, gender and race, as at 31, Dec.1994

AGE	MALAYS		CHINESE		INDIANS		OTHERS	
	M	F	M	F	M	F	M	F
21 - 39	76	37	48	30	28	6	-	-
40 - 59	50	12	39	18	18	3	-	-
60 and above	3	-	1	-	-	-	1	-
TOTAL	178		136		55		1	

Malays = 48 %

Chinese= 37%

Indians=15%

Membership is a closer reflection of the national population figures. SHO therefore is multi ethnic with members from all the major ethnic communities in Malaysia. There is however an imbalance on the gender aspect as women members do not reflect the national population average.

SHO has a policy of restricting its membership by number of members, from expanding in order that the organisation can adequately service its members. Membership numbers tend to be within a thousand members. According to one elected official of the organisation:

we have always found it necessary to restrict the growth of membership so that proper attention can be given to each, and in the eighties we reached about the maximum number who can be handled with our present capacity. (Newsletter, 1994 :1).

Vellu (22) a SHO member and service users who were interviewed expressed that he was unhappy with this restrictive policy. Vellu had this to say:

"People like to be POCAM members but membership is closed. Membership needs to be open. So many there.."

Hasan (31) another disabled person interviewed earlier who had applied for membership but his application rejected was critical and found it difficult to understand this policy. He said:

"So I think now I'm being open-minded, if they want to be like that because they are the one who set up the society, they are the beginners, so we are the late-comers. So that society something like belongs to them, it will not belong to me"

In discussing this restrictive membership policy with SHO officials, they expressed that practical and realistic considerations of the organisational ability to adequately service members was more important than having a very large membership. We will revisit this theme later especially in Chapter Nine and Ten on the role of self-help organisations to facilitate grass-roots movement.

2.3 Services Provided

Five principles serve as a basic guideline for the implementation of SHO services. Firstly, their basic philosophy is to help their members become independent and self supporting. The services provided are consistent with this ultimate goal. Secondly, SHO does not tie up its limited resources in projects such as sheltered workshops which can only benefit a small number of members. What they seek to provide aims to cater for a larger number of

people rather than being selective in approach. Thirdly, their key strategy is through individual casework which is given tremendous priority in terms of financial allocations as well as personal time. Fourthly, in order to increase their capacity and efficiency in serving members, regional committees are being set up in every State, to process their local casework in addition to the three sub-committees at the centre. Fifthly, SHO acts as a third party in the relationship between members and the Department of Social Welfare and other relevant agencies. Where there is a need SHO highlights the needs of members by making referrals and recommendations.

Self help groups like SHO play a dual role at the micro providing services to members, and at the macro dimension an advocacy role. There is therefore a commitment towards service as well as advocacy. In the case of SHO the focus on micro concerns of members is through casework and the dimension of advocacy is addressed in joint collaboration with other organisations of through MCD.

Case Work Service

SHO's primary role is to provide support to members. It seeks

to help disabled members to become independent and self-supporting, and to work for a better future for the orthopaedically handicapped in general. (Newsletter, 1995 : 1).

It is primarily focused on mutual aid functions by providing direct assistance to members through individual case-work. The aim is to assist members in the community seeking to prevent their institutionalisation in a residential home, old folks home or hospital.

Members in need make their requests known. These are processed in one of three sub-committees firstly, employment and training, secondly, welfare needs and thirdly, orthopaedic and mobility aids and medical treatment needs. The request is made by the disabled person who is a member of SHO either by letter or in the prescribed form as in the case of employment. The request is then forwarded to the relevant committee. Prior to this, if there is a need, the Executive secretary who himself is a disabled person, would make further enquiries either by a direct visit or through the phone. The sub-committees which meet monthly, discuss the needs and an appropriate decision is made either a request for further clarification, or approval, or rejection, or a call for some changes from the original request, or the Executive secretary is asked to make a field visit and make an assessment. In outstation cases and where there is a regional representative, he/she might be consulted on the matter and asked to make an assessment and send a report.

Once approved the request is immediately acted upon and there is a monitoring period of three months to follow up the case. Where a payment is made for the purchase of an item, the Society requires an official receipt. In most cases cheques are paid out in the name of the shop or agency where the item is to be purchased as indicated by the service user. A progress report might be requested to assess *how the member is performing. This is* especially so when a business grant is given for a small business. In such cases monthly account statements would have to be presented. This approach might seem paternalistic and lacking the trust of the service user, however the SHO is responsible for the funds. There is often a tension between trust and accountability but the SHO's procedures developed by disabled people themselves affirm accountability for the SHO funds.

Since the inception of SHO the Employment sub-committee has responded to 990 requests ranging from placement of members in wage-earning jobs, through assistance to be self-employed (financial grants) or to get trading licence, or to improve education or gain entry into the Government rehabilitation training centre at Cheras or to secure placement grants for finding jobs.

With regard to orthopaedic and mobility aids and medical treatment a total of 2,970 cases have been handled since the formation of SHO. This is by far the largest number of cases handled. These include giving of artificial limbs, callipers, wheelchairs, or bicycles which meet basic needs and also free operations and medical treatment.

General welfare matters include house repairs and modifications, water and electric supplies as well as funds for the building of appropriate latrines. Furthermore SHO has assisted members to obtain allowances from the Department of Social Welfare. 845 members have received welfare related assistance from SHO since its inception.

There is no doubt that the picture one gathers is that SHO seeks to support its members in their own neighbourhoods. Where necessary grant support, equipments or letters of support are provided. Through this approach they are able to service a large number of members with a relatively small staff team.

Advocacy and Public Awareness related Services

A second major focus of SHO is advocacy. While SHO's primary focus is individual casework, it nevertheless devotes some attention to bringing matters relevant to

orthopaedically handicapped people to the government and the general public. Issues, concerns and problems of a general nature common to other categories of disabled people are basically done through MCD.

SHO has seen a number of victories in lobbying for policy change as well as some frustrations. The most successful attempt was SHO members active involvement in the preparation of a code of practice for access for disabled people to public buildings. It is now mandatory by an amendment to the Uniform Building By-Laws. SHO after seven years of appeals on the payment of tolls on the motorway for adapted motor-cycles, finally received in 1994 a letter from the officials certifying exception was received. Furthermore since 1990 appeals have been made on road-tax for adapted motor-cycles, whether four-wheelers or three-wheelers and in 1994 the road-tax was reduced to just one ringgit per year.

The most frustrating experience is that in spite of MCD's protest and wide coverage in the media on the issue of the exclusion of wheelchair users on the newly established STAR Light Rail Transit System, there has been no break through in the dialogue. A closed door meeting was held with the Minister of National Unity and Social Development on 24 Nov.1994 and a further two dialogues with the STAR Light Rail Transit System. The SHO General secretary describes their experience:

Alas, nothing particularly useful has come out of this process as yet. The other side just do not want to accept MCD's proposals. They say that the provision of facilities asked for, such as lifts at all their stations, would cost a bundle. Besides that, they maintain that the presence of wheelchair-users would create dangers and cause delays to the general public. (Newsletter, 1994 : 1).

Sport related Services

Another aspect of SHO's activity is sports related. SHO is a member of the Malaysian Sports Council as well as the International Stoke Mandeville Wheelchair Sports Federation. SHO members are assisted in training as well as sent to represent Malaysia in international wheelchair games. Members have won medals in a number of regional and international gatherings. A sub-committee on Sports coordinates the SHO activities. SHO members participated in the wheelchair racing in Singapore in June 1994 where three bronze medals were won. At the FESPIC Games in Beijing in September 1994 five members represented Malaysia accompanied by two officials, SHO associate members, when three medals were won.

2.5 Finance

SHO allocates roughly 67% of its funds to casework or direct aid to members, 11% to sports and about 22% goes on overheads. In 1994 the Society provided RM \$208,00.00 in direct aid to members and only RM \$26,00.00 was for overheads.

SHO has four guiding financial policies. Firstly, they do not receive funds from the Department of Social Welfare as they do not want to be obligated to them. They want to be free of obligation especially when they are involved in an advocacy role. It therefore relies on public donations through their fund raising programmes. Secondly, SHO provides financial assistance up to the normal limit of RM2,500.00-

for any purpose which will help the member to become independent or ease their living problems such as buying a wheelchair, starting a small business or building a proper latrine. (Newsletter, 1994 : 2).

Thirdly, SHO does not provide or give loans to members. All their contributions are grants. and Fourthly, SHO does not give monthly allowances except for some special purpose such as training.

Table 12 : SHO Income and Expenditure Figures

Year	Income	Expenditure
1991	RM 312,278.00	RM 177,171.00
1992	140,655.00	171,387.00
1993	307,888.00	242,300.00

3. CRITICAL ISSUES IN ADVOCACY AND SELF HELP

Over a period of eight months (August 1994 to April 1995) in the course of the field study the researcher observed four significant aspects through participant observation at various committee meetings, interviews of service users and field visits as well as through reading SHO's documents. Unstructured discussions with elected officials, staff and members were very helpful in understanding the nature and character of this organisation.

3.1 Self-help Initiatives

SHO's strategy to improve the physical, social and economic conditions of its members through individual case work is significant. The attempt here is to enable the disabled person to become independent and self-supporting. Kassim (26) is a member of the SHO

and an interviewee. He was assisted to undertake a computer course for which SHO is paying the fees as well as the taxi fare. He applied to the SHO indicating the time of course and institution he wanted to study in. He described with sadness that since the motor accident which resulted in his impairment, he has been under pressure by his loving family to stay home.

"My father says, 'stay home, you are sick, you don't need to work, I can take care of you'. If I am not independent who will look after me when they (referring to his parents) are no longer here".

Kassim further affirmed that

"disabled people should express themselves and be in society. I read about waterskiing, parachuting, rock climbing- doing all sorts of unbelievable things but in Malaysia we are not as adventurous as them. Why can't we do?"

He acknowledged the support provided by SHO which is now enabling him to acquire a new qualification in computer studies. In the long run he will be able to earn a living for himself. Kassim said

"I want to be financially stable. I want to find my own house. Best way to get out" [of the control of his overprotective parents]. For the time being I cannot".

Osman (25) another interviewee, received an educational grant of RM300.00 from SHO to undertake a part-time banking course while he is working as a telephonist. His intention is to upgrade himself with a banking clerk certificate in order to be employed in a better paid job. His current job is poorly paid and according to him there are no career prospects. He too made a request to POCAM in writing and his request was granted.

Musa (52), who has a spinal injury due to a fall, received assistance from SHO to repair his squatter house¹ in order that he could continue to live in his home. The researcher accompanied an official of the SHO who made a visit to ensure renovations were made. The researcher observed that while Musa was confined to the bed he had the support of his loving wife. He seemed to have accepted his disability as his fate and did not see himself working again. What impressed the researcher was that although he had been an active member of the ruling political party, and his accident occurred while making arrangements for a political gathering, he had not received adequate financial and other support through the numerous schemes for example low cost housing. They expressed bitterly of how they have been forgotten by politicians.

Likewise Krishan (52), another SHO member and interviewee, was assisted with funds to install a water pipe system to his squatter house. Conversing with him in the vernacular Tamil language, he said that he had approached Indian politicians about ten times.

"I even went to the (name of the politician)'s house and asked. Now I don't go and ask them. They need to help disabled people- there is no meaning if they only assist normal people. They should focus on us"

There are numerous other examples of how SHO's direct, individual assistance is providing the only assistance to some disabled people living in their homes and in the community. It is possible that without this assistance many of them would be institutionalised in their own homes and neighbourhood. While the direct assistance provided by SHO is very

¹Affordable housing is a major issue in Malaysia. While the government has had many low-cost schemes, these are insufficient. "A squatter settlement is described as occupation of land without the permission of its rightful owners" (Hiew, 1995:12). They are part of the urban poor, whose housing conditions lack proper amenities. It is estimated that there are about 226,000 squatter in the city of Kuala Lumpur. (Hiew, 1995:12)

limited and in no terms comprehensive, nonetheless it is an attempt by disabled people to provide support to their fellow members.

Prior to our examination of SHO's case work strategy it is important to note that the Spinal Injuries Association in Britain has given little emphasis to case work (Oliver and Hasler, 1987; d'Alboville, 1991). The reason given for this is the impracticality of such provisions because of a shortage of resources and personnel as well as the fact that the members are scattered around the country. Furthermore the Association maintains that case work is incompatible in principle with self-help because self help as they see it, is about mutual aid and collective action not individualised support. We will take up this theme again in Chapter Nine and Ten when a comparative analysis is made in the light of the citizenship model of social work practice.

It is important to note the strengths of the SHO's practice as well as some of the possible drawbacks. While there is a concentration of effort on individual casework there is also some focus on the larger issues facing disabled people in general. However the casework method adopted is different from the traditional professional approach not least because that the work is carried out by fellow disabled people as opposed to professional social workers. These and other differences will be more evident from the description of the casework process which follows.

Casework Process

It is helpful for us to review SHO's casework process. The goal is self-empowerment. Although this word is not used, it is reflected in words like 'independence' and 'self-support'. The process includes a number of basic stages namely:-

Application Stage: Here the disabled member makes his need known and requests the assistance needed. This is communicated through a formal application either by the prescribed form (as in the case of an employment related need) or a simple letter describing the need. It is important to note that it is the disabled person who has made an assessment of his own need and is making the request.

Assessment Stage: Prior to an approval, the respective sub-committees make an appropriate assessment of the request. In some cases a visit by a staff or a committee member might be necessary to clarify the request made. In outstation cases and where a Regional representative is present his/her assistance is sought in making assessment. In most cases all that is requested is a verification that this is a genuine need and whether it is the best assistance that could be provided. Here again the attempt is to empower the member to clearly think through his/her request and to clarify that this is what he/she wants and to decide if it is the most helpful and appropriate. Where a request does not have a monetary implication staff handle it directly, for example a letter of support for a job application or for a licence for a small business or even legal or medical appointments. If the request is for a spare part of a wheelchair for example it is directly handled and even in urgent cases, most often of a medical nature, the Executive secretary in consultation with the elected

secretaries will take immediate action and then inform the appropriate committee at its next meeting.

Approval Stage: Approvals are a corporate effort where the sub-committee has the delegated authority of the executive committee. The sub-committees meet monthly and their decisions are endorsed by the Executive committee. On receiving the report members present take a decision. In most cases the researcher has observed that the committee is very trusting of its members and a majority of the requests have been approved. On one instance the researcher personally felt that a request by Ismail (40) one of the fourteen interviewed was taking advantage of the assistance scheme. His request was for assistance to pay the stamp duty (RM1,000.00) for a transfer of a land into his name which he inherited. The committee granted the request. After the meeting the researcher discussed the matter with a senior elected official and was told:

"the chap is not rich just because he get's a land. If we don't help, he will lose the land. It is better to give more than to give less."

Only one out of the fourteen applications for financial assistance was rejected. Even in this case a disabled member of the committee had a personal chat before a decision was taken in rejecting the request. However the SHO does take accountability seriously especially if they discover a member falsifying data.

Action Stage: Once the decision has been made the Executive secretary acts on the decision by making the appropriate arrangement to transfer the funds. In the case of a payment made most often it is in the name of the shop where the item is to be purchased as

suggested by the service user. At other times the equipment is purchased and sent off to the member.

Follow up Stage: As a rule for payments made an official receipt should be forwarded to the office. In a majority of cases there is a three months follow up in receiving performance reports from the member concerned. This is done to note the progress made and the impact of the assistance on the member. Once again it is the member concerned who gives the report and the Executive secretary communicates. Where it needs further clarification or assistance a field visit is organised. If a member has abused the funds than action is taken and depending on the nature of the offence, may lead to suspension or even expulsion from the membership. After the basic review period the case is removed from the active list. Till then it will remain in the minutes of the sub-committee and be brought up for review in every subsequent meeting.

It is important to note the part played by the individual users of the services. It is the user who determines his/her own need and this is communicated to the SHO. What the committee members do, (who are, in the majority, disabled people) is to basically verify that need and ensure that there is accountability for the funds. The user however is not part of the final decision making process. There have been cases where a request has been rejected or an alternative suggestion been made. In all these cases the individual user is consulted.

This approach illustrates one model of collective effort of disadvantaged people assisting their own through mutual support. Later in this chapter we will reexamine this approach

which is modeled after a charity based approach. There are alternative approaches where decisions are made in a collaborative way. However there is a strong feeling that if the SHO does not help, the only option for many disabled people is to seek admission to a residential centre or face the reality of being institutionalised in their own homes and isolated in their neighbourhoods.

It is further important to note that SHO has a very good working relationship with the Department of Social Welfare as well as other voluntary agencies. Where appropriate, cases are referred to other agencies for their assistance and support. Herein lies its strength, where there are other avenues for assistance SHO would tap them and where none is available it would utilize its own resources to provide the assistance needed. The elected officials representing the total membership are entrusted with this task.

Of the fourteen who were interviewed only one had received a negative response. Cheng (37) is a manufacturing assistant working in a micro chips production factory for the past 17 years. She applied for a grant to purchase a sewing machine in order to do tailoring as a means to generate more income. SHO decided against her on grounds that the funds they gave out were to members in desperate need.. In their assessment Cheng had a stable job and also owned her own flat. To them she could not be regarded as being in desperate need. The Chairman of the Employment sub-committee discussed the matter with her prior to the decision being taken. Cheng's remarks reveal her lack of appreciation for the needs of others.

"If SHO does not give I'm not happy. Need the money to buy the sewing machine to earn more money. First time asking".

SHO does apply a means test in assisting the members and expects 'the more well to do' among them to assist others rather than being a recipient.

SHO has produced a self-help guide entitled 'What the Government and our Society can do to help you' (1993) which is distributed free to members. It is a question and answer write up in two languages, English and Bahasa Malaysia. It is a very comprehensive and practical guide on all the major questions relevant to disabled people. The intention is to help the members be well informed of the services available and how to take advantage of them. Information is essential for the empowerment of disabled people. Areas covered include matters pertaining to registration, medical treatment and equipment, employment allowance, housing, education and rehabilitation services available. This is the only comprehensive guide available in Malaysia for physically disabled people. Information is an important aspect of disabled people's independence and therefore very useful.

One major shortcoming of the case work approach is as Razak notes, "if member does not contact and highlight, SHO also keeps quiet". This raises the issue of who is taking advantage of the assistance provided. In the current approach a member makes his/her request known and SHO responds. As one SHO committee member acknowledged that

"bold face members might apply for everything, others are shy and won't apply. Difficult to really know unless we have a very intensive system and currently by the time we know, its too late".

At the March 31, 1995 brainstorming session on employment related issues this matter was acknowledged to be an issue which must be addressed. A recommendation was put forward to the executive committee, that an annual review is made of all employment casework. SHO is planning to develop an annual report system where an overall assessment of

members situations is made. SHO employment sub-committee made the following recommendation to the executive committee:

In the current practice members approach SHO for assistance and SHO responds. A member's business has its up and downs; if he hits a bad spell and is reluctant to ask us for further help, we may not find out until too late.

A simple form will be designed to be sent periodically to all self-employed members to check whether their business is improving, or steady at a satisfactory level, or in need of further help from us. It will be sent out in odd-numbered years, when in need of further help from us..(Proposal, October 1, 1995)

Need to move beyond individual casework to group work

However what has not yet developed in SHO is a group and community oriented approach. Oliver and Hasler (1987) recognised the potential of community work or community social work methods. In their experience they found that the problems faced by disabled people were essentially practical ones.

SHO currently only does individual casework and has not ventured to other approaches such as group or community approaches. Its officials say that due to their limited resources this is the best they can do. Other approaches will require more staff and funds and this is beyond the current capability of SHO. While help to individuals is useful and targeted, it fails to tap the group solidarity and joint effort that is an integral dimension of the self-help movements.

SHO is modelled after the charities model rather than the genuine self-help tradition. This is because what SHO has managed to do as a registered society is raise funds through public donations and re-channel on a need basis to fellow members. The major difference of SHO from other charities is the fact that it is an organisation run by disabled people and

it does not subscribe to a residential or institutional approach to rehabilitation of disabled people isolated from mainstream society. What SHO has not explored sufficiently is how can fellow members in smaller groups throughout the country provide mutual support to each other. How there can be greater collaboration of grass root members in an attempt to enable each other.

A general observation is that even within the disabled community there is a dimension of charity and paternalism, where better educated or more financially stable disabled people seek to be doing 'a good turn' to other disabled people. An element of paternalism could prevail especially when a majority of those holding office in the Executive Board or the sub-committees do not themselves receive any funds from SHO. It is therefore imperative for SHO to tap the self-help potential rather than making a majority of their members passive recipients of services provided.

Yusof (36) a member since 1975 and a recent recipient of an employment grant is critical of SHO's approach. He indicated that currently members expect to receive what they ask for.

"Members ask and they think they will get; if they don't get they don't want to continue. It is more for personal gain and not to contribute to others".

He went on further to describe the notion "the child of welfare" namely that it is a receiving mentality. Many SHO members received their initial training at the rehabilitation unit run by the government in Cheras. In his assessment it oriented them towards welfare dependency. Although living skills were taught and they were prepared for independent living their mind set was not changed from welfare in order to compete effectively in the

open world. This is why many who have received funds from SHO keep coming back for more. He felt that SHO should explore other avenues than the current approach of direct contributions. Yusof said,

"If SHO changes its approach then members will be more self-reliant. SHO should start loan schemes or even a cooperative".

This idea of a cooperative has surfaced on two other occasions during the field study. At the April 1994 workshop two participants expressed the need. Misbun (30) one of the interviewee expressed it during the interview too, saying:

"There is an urgent need to focus on economic issues. In my context I have tried to get some friends and started a cooperative. This will not only provide training but serve as an umbrella body for disabled people interested in business".

At two discussion groups with the employment sub-committee, the researcher reported some of these views to explore alternative approaches which are group oriented. The sub-committee after discussing this point in detail resolved that will visit other projects run by self-help groups which have adopted a group approach. The recommendation to the executive committee was:

Exposure opportunities and talks by NGOs in economic development programmes will be organised for Employment Committee members; the purpose here is to learn from other examples and to foster networking with other groups. Two examples are Amanah Ikhtiar Malaysia (AIM) and the Credit Union Batang Berjuntai. If found suitable SHO members in the areas concerned might be introduced to these programmes. (Proposal, October 1, 1995)

While one can conclude that this is a cautious statement, however there is some openness to explore other approaches which have been adopted by other self-help groups in Malaysia which is group and community based rather than individual case work. The approach adopted by AIM which is a Grameen replication operates the poor organising themselves

in small groups of five members and six such groups form a centre. Thas and Getubig (1993) observe:

This form of grassroots organisation not only promotes solidarity and participation amongst the members at the group and centre level, but also promotes mutual support. (Thas and Getubig, 1993:16)

In SHO providing for its members, its strategy has not been to recruit every orthopaedically handicapped person who has applied for membership into a movement for all orthopaedically handicapped people in Malaysia. Their policy since the 1980s has been to restrict the growth of the membership. However a small number of new members are accepted

to replace losses, limited either to a particular region or to a particular group such as spinal damage paraplegics" (Newsletter,1995).

However a number of members interviewed feel that there should be a change in the policy towards admitting all physically disabled people who apply for membership. Vellu expressed that "SHO needs to open up its membership". Likewise Ratnam is not happy with this policy and believes that more should be allowed to join.

An open membership policy could have been adopted by SHO in order to enable as many physically disabled people as possible to become members. Here is where SHO could have fostered and facilitated the birth of grass root disabled peoples organisations mushrooming all over the county. However this approach poses a problem as indicated by SHO officials namely the accountability of these new groups. SHO hope to develop branches in every State but will still not open up its membership. In so doing it fails to provide an avenue for a majority of orthopaedically disabled people in Malaysia to be part of a self-help

group. Furthermore it has not entered into an extensive programme of educating disabled people at a national level into being independent or self-supporting.

3.2 Efficient Organisational Setup

SHO is a well organised society and their scheduled meetings are very impressive and indicative of the dedication of the elected officials. Without fail each month the three main case work sub-committees meet in the same week for example Thursday - Employment, then Friday - Welfare, Saturday - Aids and Medical and finally on that Sunday it is the Executive committee. This systematic schedule enables effective execution of the organisational task. It further facilitates a joint decision making process.

Their computer data base on records of members as well as the case work, puts SHO ahead of a majority of the voluntary organisations. It was felt that with about 1,000 members and reference to over 4,000 case work records the only efficient way to handle the data was to computerise the whole system. This data base is complementary to the traditional filing system which contains all the records of the members. The data base, which is frequently referred too during a meeting, indicates at a glance assistance provided to a member since he or she became a member. Furthermore a key word search could give information on the basis of geographical location of a member or similar cases assisted. This enables SHO to be consistent in the decision making process.

The administrative and coordinating capabilities of SHO are a clear verification that disabled people can efficiently and effectively run their own organisation, raise the funds needed and ensure public accountability.

3.3 Level of participation among members

Collaboration of disabled and non disabled people

SHO puts to good use the collaborative effort of joint action by disabled people and non-disabled people who play a supportive role. It is the disabled person who has the right to nominate as well as elect non-disabled people in SHO. In so doing they have reversed the power base which tightly controlled other voluntary organisations where non-disabled people hold power and are in control of the organisation. The SHO example affirms the need for non-disabled people to play a supportive role as allies, or friends. The non-disabled person is there in the committee on the invitation of his/her disabled friends. There is therefore no undue pressure by non-disabled people on disabled people. Further, only those non-disabled people who affirm the leadership of disabled people and respect it are invited into SHO. Herein lies the strength of SHO, while they affirm the independence of disabled people they also acknowledge that in reality they are all inter-dependent and therefore see the place of non-disabled people playing a part in enabling the self-support of disabled people. It is significant to note that the SHO executive consists of nine ordinary (disabled people) and six associate members (non-disabled people).

Wider participation of members

SHO has about 70 active members serving in various capacities at the national level. There is a hard core of about 10 people, in the researchers assessment who are the, 'life blood or wire' of the organisation. Some members like the Founding Secretary have made sacrifices in the formative years to ensure the organisation is well established. One clear example is the organisation started operations from the secretary's home which was the base till the middle of 1994 when SHO acquired its own building to house the office. The

core group comprise respected members who are also leading disabled people in Malaysian society. They have tremendous influence in changing some government policies as well as in setting up the Malaysian Confederation of the Disabled. Some members expressed concern that things would not be the same if one or two of them stepped out of office. Its current organised nature is directly a result of their influence and supervision. The organisation is moulded in their character.

On a personal level at least one from with the core is noted for his very kind hearted and generous nature which is also reflected in SHO's approach to members, especially in its generous contributions to support their independence in the community. There are clear attempts by the core group to promote leadership among younger leaders from the membership. Key positions like general Secretary and Assistant Secretary as well as that of the Executive Secretary are now held by younger members. The researcher observed three or four of these younger leaders working with core older leaders preparing for meetings and working out the details of the minutes after the meetings . In many cases they travel around together visiting members too. There is, therefore, an apprenticeship model of leadership training.

While these are the strengths of individual personalities there can also be draw backs in the case of overpowering personality. In meetings very seldom will any one object to recommendations or suggestions made by some core members. As one member commented "if so and so says yes, no one says no, because he has that kind of experience". Due to maturity and dedication of the core group members it is very unlikely, even if there are

disagreements, for any one to express it openly. This is culturally sanctioned in Malaysian society where respect and honour of elders in the community is observed.

SHO is yet to activate a large part of its membership. Apart from the newsletter (four issues a year) and the Annual General meetings, there are seldom group gatherings organised. A number of years ago a leadership course was held for committee members, especially those in regional committees, to be oriented to SHO policies. There are no regular awareness meetings on key issues or struggles of disabled people. As a number of members commented the organisation does not seek to mobilise the strength it has. According to the committee they cannot focus on too many activities and their priority is casework in order to assist individual members. Therefore many members are not oriented to the issues and struggles of disabled people in general at a national or international level. What seems to be emphasised is an individual and narrow focus on individual problems affecting self support and the ways to overcome it at an individual level with the assistance of SHO. It is at this level that many members are active. Where SHO could strengthen is group based approaches where more members are involved in smaller self-help groups supporting one another. This SHO has not tapped the potential of the independent living units of the United States or the integrated living unities of the United Kingdom as discussed in Chapter Three.

While SHO does focus on advocacy issues, it is micro matters like road tax or toll which seem to be the concern of many of the SHO members. The wider macro issues of a disabling environment are not shown as urgent on their agenda apart from the core SHO leadership addressing them through MCD.

One wonders if the socio-political climate encourages this level of change rather than a strong orientation to the rights tradition as demonstrated by the disabled peoples groups in the West. It is important to affirm that those in the executive committee are regularly briefed and they discuss the national and global disability issues. They represent the organisation at national and international gatherings. However, these have not trickled down to the grass-roots in mass awareness and mobilisation in addressing the root causes that disempower disabled people in Malaysia.

Participation of disabled women in the sub-committees and the executive committee is clearly lacking. There are none in the executive committee and in the sub-committee there is only one. One reason is that out of every 5 members only one is a woman. Furthermore as in others cultures disabled women in Malaysia are also likely to be more disadvantaged than men. In the fourteen cases processed by the employment and welfare committees in the Klang valley, during the field study period, only two were by disabled women. There could be discrimination against women in SHO. Although not acknowledged by the Committee, some of the policies favour disabled men as opposed to women. One example is the grant on house deposit. On the purchase of a house a member could receive RM1,500 towards the down payment if a male applicant but a single lady will only receive RM500.00. The rationale as explained by one SHO official is that single women would not live on their own but would have another friend or family member who will be making a contribution towards the purchase of the house.

Of those interviewed only one was serving in the committees or actively involved in any capacity. Interviewees cited a number of reasons for their inability to be involved. For a

majority transportation was a problem. In order to get to the meeting they would have to take a taxi and this was beyond their means. SHO does not provide assistance for members to attend meetings. For others, while they are in the Klang valley, the distance is a problem. For some it is the nature of their work, especially if they are employed in a factory with shift work, which makes participation impossible. One member clearly felt he lacked the confidence to be part of the committee as he had no formal education. Lim (43) expressed this clearly which was expressed in the vernacular Malay:

"I not active in SHO. Did not go to school, so don't know how to talk in meetings. I go AGM but don't speak. My family was poor, so did not send me to school. Also did not have wheelchair. So it is difficult for me".

On the other hand Vellu expressed:

"Not active-lah. Work because I am in shift work is one problem but also I feel not much opportunities for interaction. No chance to meet others in a personal way-only at the AGM".

These issues will have to be seriously considered if SHO wants broad based participation from a majority of its members. Small groups in different neighbourhoods with delegated tasks or activities might be one way out. For a majority it still seems to be a lonely attempt to face a disabling environment in their own neighbourhoods.

3.4 Tapping the potential of the market

With Malaysia's high performance in the global economy and Malaysia's vision to be industrialised by the year 2020, the market provides an alternative route to liberation for disadvantaged communities. For a long while development workers have focused on a strategy of redistribution; now there are opportunities to take another path namely 'wealth creation'. SHO has in many ways tapped this potential in order to enable its members to

operate viable small businesses in the market place. SHO's contribution in this area is impressive as they have supported 595 small businesses as compared to placing 165 people in wage-earning jobs since they were founded.

Of the fourteen interviewed five are in small businesses and their experience is really enriching the prospects of tapping this route for disadvantaged communities. In all these cases they did not have any formal education and so their prospects in wage-earning employment were difficult. They would have to learn a new skill or be trained to work in a factory. Furthermore for many wage earning employment was too rigid in the working hours as well as posing transportation difficulties. Faced with these obstacles in society the route of small business is an attractive alternative. The economy that has a high growth rate of 8% requires small businesses to supplement and complement the larger businesses.

For most of SHO members the main difficulty was with the initial working capital needed as well as in securing introductions to appropriate officials for permission to run the business. Elsewhere studies have indicated that the poor have the capacity to survive and their main asset is themselves (Joe Remenyi, 1991; Getubig *et al.*, 1993). SHO provides an initial business grant of RM \$2,000.00. *In other cases it has provided a larger grant of up to RM \$4,000.00 depending on the project.* Members run successful businesses such as food outlets, tailoring, furniture making, radio and motor cycle repair shops. The assistance provided by SHO in requiring them to plan as well as keep proper accounts is helpful to ensure success. Ratnam (34) expressed this strongly when he said:

"Not happy with SHO, still need to improve in certain areas especially those doing new business - more personal visits to encourage, organise business training. Need to run this in Malay [vernacular]. Also motivation seminars."

Singam (36) another interviewee who runs a grocery stall with his non-disabled wife in a squatter area said in vernacular Tamil:

"My problem is ideas on how to improve the business. It is small. I buy items from the shop out there daily-problem not enough capital to buy more. Also I cannot read or write, cannot count well. My wife help me".

Lim (43) also expressed need for input for business expansion as he has reached his maximum capacity in running his furniture making workshop at the back of his rented house.

"To expand need place for workshop and sales place. Need workers. Need capital, at least RM10,000.00. I need support to make big, if not till old I will make only in small place".

In the course of the field visits it was established that SHO members involved in these small businesses fell into three categories. Firstly there were members who had a desire but no experience in setting and running a small business. They want to start but lack the experience and know how. Secondly, there are members who are running struggling businesses. The difficulty might be as a result of a lack of product knowledge, or marketing strategy or even inability to keep proper accounts. Thirdly there are successful businesses but the members are frustrated that they are trapped in a system which will not enable them to enlarge their business and as a result they cannot generate additional capital. There is no further growth prospect. This often is a result of a lack of capital, need for bigger premises or workers needed for the expansion. Others within the membership outside self employment were either employed or unemployed. According to SHO officials the unemployment rate among members was low.

This situation demands an appropriate response and one is doubtful if SHO has the capacity to follow through and assist all the categories and stages in business development. It is however possible to say that SHO has the ability to respond to categories one and two, where they have sufficient expertise to assist fellow members in the initial stage of the business. There is the possibility that SHO will organise a small business course to assist members. It is intended to be basic in order to ensure that members are street wise in handling business matters. Other members who have developed successful small businesses could serve as resource persons. It is however those who have moved beyond categories one and two, who need outside assistance. This is primarily for the expansion of the businesses. This will ensure that there is an increase in profits. SHO plans to establish links with other agencies in the community which have been set up by the government for business development. It would be appropriate for disabled people to be incorporated into these facilities alongside non-disabled business people.

The SHO's employment sub-committee discussed these matters and has recommended to the executive that appropriate action be taken especially to assist members in different aspects of their business. One area they will explore is channel their members to other appropriate government or private sector agencies that provide professional support to small businesses. We will revisit this aspect in Chapter Ten.

Herein lies an alternative route for some in the poverty cycle to break loose. In the initial or incubator stage to be directly under the direct support of SHO but at some point to be set free in the open market to compete with all the others. There is a need for new specialist organisations from a business and professional rather than a welfare tradition

providing the support. In the case of members interviewed who ran a business four of the five were well established businesses. Yet they turn to SHO rather than a bank for loans to give them the additional capital they need. From the Grameen experience business which starts from a welfare footing will remain trapped within it. The successful micro enterprise projects around the world has relied on small loan with interest, using a self-help group approach. (Remenyi, 1991; Getubig *et.al.*,1993) SHO officials do admit that they do not have adequate feedback on the current status of their members in business. From the five interviewed they have benefited from the grants provided and are open to meet up with others in SHO to discuss experiences with the view of providing mutual support.

4. Chapter Conclusion

The self help movement among disabled people emerged in the late 1960s and the 1970s both in industrial and developing countries. The main reason for this development was the dissatisfaction of disabled people with regard to the services that were provided for them both by the public and voluntary sectors. *The experience of SHO is similar to organisations like the Spinal Injuries Association in Britain.* Both these organisations see their role as complementary to other approaches but in so doing challenge non disabled people's domination in service provision through alternate models. What emerged from this critical review was the essential need for disabled people themselves to be involved in the planning and delivery of the services. Furthermore the partnership was noted in that the disabled people saw the role of non-disabled people and invited them to play a supportive role. This was done on their own terms rather than by non-disabled people. The role of non-disabled people as resource workers was affirmed both by SHO and by disabled people in the West with the role of non-disabled people determined by disabled people (Oliver 1990, 1996).

However a similar partnership has not developed in CCO organisations where non-disabled people see the role of disabled people as recipients. This aspect will be further discussed in Chapter Ten.

The more difficult dimension to analyse is the issue of self-help groups and new social movements. Oliver (1990) develops arguments to consider the disability movement as a social movement. One clear indicator for this is the role of the new movements:

in placing new issues on to the political agenda, in presenting old issues in new forms and indeed, in opening up new areas and arenas of political discourse. (Oliver, 1990 : 130).

The difficulty with the Malaysian experience is, while it is true that disabled people have organised themselves and are challenging inappropriate social responses by the wider community, this involvement in challenging the unjust structures is played by only a handful of better educated disabled people rather than seen as a wider movement of protest of disabled people at the grass roots. In the UK one reason for the inability of the grassroots to identify with the wider policy and political agenda of the disability movement is the "tendency to down play the role of impairment of the physical condition" (Shakespeare, 1993 : 256). A majority of disabled people at the grassroots are more concerned about the practical day to day problems that affect them such as economic and social security. SHO at this point in time has devoted most of its efforts to addressing the concerns at the micro level of individual members. In some ways it is caught in a vicious circle that the immediate concerns are urgent and without addressing and devoting more attention to the macro the micro will continue to dominate their agenda.

Alongside this difficulty is the issue of truly seeing the disability movement in Malaysia as a mass movement of disabled people. Unlike the western counter-part organisations, which have grown in membership, organisations like SHO have restricted their membership and in so doing help to delay the process for the empowerment of more disabled people in Malaysia. We will explore this theme of opening up the membership as well as the development of more grassroots disability societies in Chapter Nine and Ten.

**DISABLED PEOPLE AND VOLUNTARY ORGANISATIONS
A COMPARATIVE ANALYSIS**

1. Chapter Introduction

In Chapter Six we critically analysed data gathered from thirty-one direct service providing voluntary organisations. A four-fold typology evolved from this analysis, where a majority of 'organisations for' were categorised as charity care and enabling care while 'organisations of' were categorised as advocacy and self-help. An in depth study of two organisations, one an 'organisation for' and the other an 'organisation of' was the focus of critical analyses in Chapter Seven and Eight.

Having provided a detailed description and analysis based on field study on the two organisations, this Chapter presents a comparative analysis of the organisations and the approaches. This analysis and comparison is based on earlier work done on the typology of voluntary organisations developed in Chapter Six and the citizenship model of social work formulated in Chapter Three.

The comparative analysis in this chapter examines firstly, the services provided and then the structure of their delivery. The analysis is then extended to compare the four-fold typology with the citizenship model of social work practice. The field studies and this analysis aim to provide an appraisal of social work theory and practice, as well as voluntary agency policy and structure. Chapters Six to Nine provide the ground work for the reformulation of the citizenship model of social work practice appropriate for the Malaysian context which is the focus of Chapter Ten.

2. COMPARATIVE ANALYSIS OF CCO AND SHO

While the two organisations under study have major differences there are three similarities. Firstly, both are registered societies with a membership. Secondly, they both provide services to physically disabled people and thirdly, both have their base in the Klang valley. The in depth study reveals the nature of the differences and its impact upon disabled people. Two major areas are the focus of this section namely, the services provided and the structure that facilitates this in the two organisations.

2.1 Comparative Analysis of Services Provided

With regards to services we will examine three essential areas to highlight the differences not only in the type of service provided but also in the priorities set which are based on differing understandings of disability.

2.1.1 Residential and Community Services

The charity care organisation's (CCO) main objective is the running of the residential home and the provision for the maintenance and welfare of the residents as described in the Chapter Seven. Residential services are provided for forty-four residents, some of whom have been in the home for the past twenty-eight years. In a brochure, CCO states that its residential service does not create an institutional atmosphere but a home environment. It does not go on to explain the difference or what is meant by a home environment' or 'institutional atmosphere'.

It is therefore helpful to draw from Erving Goffman's (1961) analysis and description of total institutions. Goffman defines a total institution:

as a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life (Goffman, 1961 : 11).

He goes on further to describe the central feature of total institutions as a breakdown of the barriers ordinarily separating three spheres of life namely sleep, play and work. Four features are highlighted:

First, all aspects of life are conducted in the same place and under the same authority. Second, each phase of the member's daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. Third, all phases of the day's activities are tightly scheduled, with one activity leading at a prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials. Finally, the various enforced activities are brought together into a single rational plan purportedly designed to fulfil the official aims of the institution. (Goffman, 1961:17).

These features are helpful for us to understand the nature of an institutional setting. In the case of CCO a majority of the residents are long term residents and have therefore developed a pattern of lifestyle and routine. Secondly, most of the activities centre around the meal times. This schedule sets the time table for the residents. Lights out is at 10pm each night. All the forty four live in one compound although they have separate rooms. They are in single rooms which provide them with some privacy but they share common toilets. A majority spend most of their time in the residential centre and those who go out regularly travel in the Home's van which takes them either to a sheltered workshop or open employment. Only two of the forty four residents own their own transport. Apart from the Home van, the residents have to rely on taxis which are expensive or on friends or family members or volunteers. The staff work on a shift system. Although CCO says it runs its home as a homely environment in actuality it has institutionalised a majority of the residents.

In contrast self-help organisations (SHO) does not provide residential services. Their belief is to support their members in the community in order to prevent them from being institutionalised. They provide assistance by way of grants to adapt existing homes in order to enable disabled people to live in them. For example grants are given to build or modify an appropriate toilet or in some cases even to rebuild the house or build an extra room. Down payment grants are given in order to purchase homes. This grant is helpful for initial booking and payment of legal fees as the balance of payment could be arranged by a bank loan. SHO has assisted members to either buy or rent low cost flats or houses from the City or Town councils (local authorities) by supporting their applications and making representation. SHO also assists members to purchase motor-cycles or three wheel cycles in order for members to be mobile. They have supported member's applications for grants from the National Welfare Foundation for the purchase of these vehicles.

Here then lies the main difference between CCO and SHO, where the former *segregates* disabled people whilst the latter enhances their living in the community. However, the recent move in CCO toward a community based approach to serve a larger number of disabled people in the community surrounding the Home is encouraging. The newly established District level committee aims to reach every disabled person in the district. The focus is in reaching new people in non institutional ways. While this is in the right direction, for the forty-four residents the Home has not been open to any suggestions of group homes and independent living units. Furthermore CCO's admission of the last two residents further illustrates this. The latest two residents are both employed in wage employment and own their own motor-cycles. In many ways they could have been supported to live in the community. However CCO has provided them accommodation

within their compound. One of the two interviewed commented that the only reason he is applying to CCO is because there is a lack of affordable and accessible accommodation in the community. In moving into the Home the latest two residents have to abide by the Home rules and regulations there-by losing some of their independence and freedom. They do so because they have no alternative. As they are not members of SHO they cannot seek their assistance and further more because of SHO's restricted membership they would not be admitted for sometime.

One possibility for change, as hinted by a CCO Council member, is to develop independent units within the compound where residents could live independently, prepare their meals and be free to organise their own daily schedule. One practical problem, as indicated by this Council member, is that because most have lived for a long period within the home they might find it difficult to be in a unit outside the compound. Goffman called this "disculturation" -

an 'untraining' which renders him temporarily incapable of managing certain features of daily life on the outside, if and when he gets back to it. (Goffman, 1961:23).

However if independent units are developed and supported by CCO outside the CCO community all the current residents must be given a chance to take a decision on the matter and be provided the appropriate support to ensure effective integration in the community.

2.1.2 Employment Services

Both organisations have identified employment services as a major area of service. There is, however, a major difference in emphasis. SHO has largely assisted its members into self employment by providing grants and training opportunities for small business development.

There is an important reason for this approach, as a majority of disabled people would not have had the opportunity to receive formal education which is crucial to secure a job in open employment. The jobs which would be more suitable would require higher levels of education. Therefore assisting a member to run a small business is an effective way of ensuring that he or she is self-supporting. Providing the initial working capital, encouragement and advice is helpful. SHO also provide a 'top up grant' if the initial grant provided was inadequate. They provide assistance to secure a licence and even a shop or stall from the local authorities. In addition SHO has assisted members in wage earning jobs by providing letters of recommendation, providing a work placement grant to ensure funds before the first salary is received and even training grants in order to up-grade a members' opportunity in the open market.

In the case of CCO a majority of its residents are in some sheltered workshop either run by CCO or other charitable institutions. Residents see themselves as trapped within this work situation. Many have commented that there is no future in the jobs they do and they are unhappy with the pay. It is demotivating and does not enhance their sense of personal worth nor provide the funds needed to be financially independent. It does not place them in a situation where their training and work experience will enable them to live on their own or with others in the local community. From the perspective of most charities, what is essential is the fact that the work routine keeps the resident occupied and it is part of therapy rather than a way of self-support. The Home serves to guarantee all basic needs. They fail to realise that financial independence is a key to empowerment. In this context SHO has got its strategy right by enabling their members to operate in the market place with some back up support and assistance.

Both SHO and CCO have inadequate numbers of staff working as placement officials. In the case of SHO with the assistance of committee members the Executive Secretary allocates a major portion of his time for this role. SHO is seeking to employ another administrator to shoulder more of the administrative task in order to free the Executive Secretary to make more field visits. In the case of CCO where employment is indicated as having high priority, there are no staff allocated to assist residents nor is there a reporting mechanism on the employment matters. No evaluation has been made of the sheltered workshops nor is there any discussion or follow up of those in open employment. CCO too has a small number of the residents doing direct sales of items like food stuffs, canned drinks, cards and lottery. They are the most neglected. As indicated earlier these are seen just as activities to occupy the time of residents rather than a means of achieving economic independence and self support.

2.1.3 Advocacy

A major difference between 'organisations for' and 'organisations of' is their commitment to advocacy. Commitment to advocacy in terms of direct involvement in policy change is another indicator of an organisational practice being consistent with the Citizenship model of social work practice as developed in Chapter Three. While CCO avoids making any comment on this in its Constitution and brochures, SHO makes a clear declaration of this in their Constitution and reports on advocacy activities in its newsletters and annual reports. SHO states in its constitution that one of its objectives is

to make recommendations to the government, and to advocate and promote laws, amendments to laws and other government regulations in the interest of the orthopaedically handicapped. (Constitution).

This it does in a number of ways. Firstly on matters directly affecting orthopaedically handicapped people it would make direct representation to government or other agencies. However on major issues that also affect other disability groups it would handle the matter with other disabled people's groups under the Malaysian Confederation of the Disabled (MCD). Secondly, while SHO networks and works closely with the government, especially the Department of Social Welfare, it has refused to receive a state grant through the Welfare department. SHO officials explain that they do not want to be obligated to the Department as in most cases it advocates for members against the Department. The matter might be further complicated because grant receiving agencies from the Department of Social Welfare have to receive a welfare officer as an ex-official in the Executive committee or council. In fact two officials represent the Department.

CCO on the other hand works closely with the Department of Social Welfare and networks with other voluntary organisations in the State Social Welfare Council. As yet the Home has not addressed advocacy related matters affecting disabled people in Malaysian society. It is in an influential position to work from within the framework of policy makers. However as CCO is not oriented to this end it is an unexplored avenue. In the context of the community based rehabilitation programme CCO serves as the secretariat and the Department of Social Welfare has been providing most of the funds for this outreach programme into the community.

While SHO is active on advocacy issues it has not developed an enlightened, politically conscious grass roots membership, who are well versed on the issues and rights of disabled people. At the grass roots the concern is for immediate needs or micro issues with which

they can identify and for which they can campaign. One clear example is the road tax or toll to be paid. However on macro level issues, the wider membership is not well versed and involved. A handful of elected officials make some representation. SHO therefore has a long way to go in terms of developing in-house awareness programmes as well as leadership programmes to develop this potential among the membership. SHO has tremendous potential in this area as it has a large membership scattered in every state in the country. A national consciousness programme could be organised for the members. In the long run members in different parts of the country could be mobilised for national campaigns and public awareness programmes.

The disability movement is faced with the cultural and political realities which we discussed towards the end of Chapter Two and Four and therefore obliged to work within the constraints of the Malaysian experience of democratic freedom. We have noted creative attempts by disabled people and will discuss in Chapter Ten some other options available.

2.2 Comparative Analysis of Organisational Structural Matters

Structures are created in order to facilitate the delivery of services. Matters discussed in this section will reveal that certain structures will facilitate user involvement and empowerment of disabled people whereas others will disempower them. Legally both organisations have a similar type of registration, they are registered with the Registrar of Societies, however their orientation and approach is different. Four structural matters are compared in the analysis of the two organisations studied.

2.2.1 Membership Structure

As both CCO and SHO have a similar registration, the main organisational provisions in their constitutions are similar. For example both organisations have a membership provision, and Annual General Meetings (AGM) which elect the principal officials. In the case of CCO the membership provision does not encourage or inhibit disabled people from becoming members. Membership structure makes provision for non-paying (contributing subscription) full members. In practice as an 'organisation for' which was set up by non-disabled people, they have not accepted disabled people as members in the past thirty years. The absence of constitutional restrictions prohibiting disabled people is a good indicator, and with an attitudinal change disabled people could be recruited as members. It is by convention or practice that CCO have not admitted disabled people as members. CCO have about thirty members in the society and while in principle it is an open society, they do not have a recruitment drive for new members. Membership in practice is by invitation. The membership structure can be small as the constitutional requirement is that the AGM must be attended by double the number elected to the Executive Council.

In the case of SHO ordinary membership is open only to orthopaedically handicapped people whereas associate membership is open to others. This indicator distinguishes the two organisations namely an 'organisation for' and 'organisation of'. The emphasis here is that disabled people can play a leading role in organising matters affecting them and taking responsibility for themselves. While SHO has about a thousand members they have introduced a restrictive policy as they feel they do not have the resources to expand. SHO in one sense has not had the vision to encourage the development of other disability organisations in other parts of the country. SHO could assist the formation through

leadership training on matters related to registration and developing programmes as well as fund raising. There is a large number of physically handicapped people who are not members of any self-help organisation.

2.2.2 Leadership and Decision Making

In SHO only disabled people have voting rights as ordinary members. They can if they decide, nominate and elect a non-disabled person into the executive committee. However the non disabled people do not hold voting rights. SHO acknowledges that they can work in partnership with non- disabled people but on their terms. CCO makes no such provision for disabled people. Furthermore all the Council members in CCO are well placed people in Malaysian society and a majority are women and wives of influential politicians or businessmen. Neither disabled people nor residents serve in any capacity in the Council or its sub committees. Decisions are taken for them, and this is very evident in the comments residents about to the new building constructed recently, namely the new administrative block, hall and the main dining and common room areas. A number of residents interviewed had concerns over the inaccessible structures constructed. None of the residents were asked for their opinions and views on the construction of the new facilities. The only formal provision is the Residents Disciplinary Committee which from the comments of the residents does not seem to be effective. The residents have some responsibility for the recreation, their personal hygiene and the cleanliness of the home as three resident committees were set up. While this is a step forward it does not go far enough to enhance user involvement in major decisions that affect their life.

While SHO facilitates disabled people's direct involvement there is a lack of effective mobilisation of grassroots membership. It is said that only about 70 of its 1,000 members are active. This therefore means that a majority are passive. This aspect is not compatible with the citizenship model which promotes activism. Furthermore while individual service users identify his or her need, for example an employment grant, they are not directly present when the decision is made. There could be a class distinction among the disabled people, as those in elected office have better jobs, are better educated and own their own transport as compared to those receiving the grants. Of the fourteen interviewed only one is member of a sub-committee. All the others only attend the annual gatherings and do not play an active part in the affairs of the organisation. SHO must develop grass root opportunities for their members to be part of the movement.

2.2.3 Staff and Volunteers

CCO has a staff team of 20 full time staff none of whom have a disability. They are task oriented rather than people focused. As the focus of the Home is residential service the majority are domestic staff who do not have the understanding or orientation of disabled people as equal human beings and citizens. Their framework is dominated by an individual and tragedy model of disability. Even though they are not professional they have a lot of power and control over the residents. The volunteers likewise come to assist the residents within this framework of the residential setting. A visitor to the home will see disabled people as unfortunate, helpless people. They are therefore moved with compassion to do things for them. Often some of the residents also take advantage of this dynamic and they too play this role as receivers which by now they are cultured to play. This further reinforces the dependency model and the residents are caught within this cycle unable to

break out. This is where, if residents have a greater say and opportunity, they would be able to reorganise the volunteers to support them in areas that matter to them most. A number have good suggestions for example concerning outings or specific support they need. The main difficulty in a home of forty-four is giving space for each individual's voice and choice. Due to this difficulty individual identity is lost in the collective programming of the home. The staff are not oriented to empowerment issues nor are they playing a supportive role alongside disabled people.

SHO operates its programmes with only two full time staff. Their role is different. As both are themselves disabled they play a supportive role to their fellow members. They do not take control, or take over the situation, but implement the decisions of the committee in cooperation with disabled people. The committee members, a majority of whom are also disabled also play a direct part in providing support to the members. SHO has effectively recruited the support of a number of professional non-disabled people namely their royal patron and their legal and medical advisors who are leading influential people in Malaysia society. They serve in that capacity on the invitation of disabled people. In contrast CCO has not utilized disabled professionals in their programmes.

2.2.4 Fundraising

Both the organisations have the tax relief benefit for contributors and as a result the general public, especially the private sector companies, take advantage of this and make regular contributions. While CCO receives an annual grant from the Department of Social Welfare, SHO does not. SHO however does make representation on behalf of members to secure direct assistance from the department.

The major difference is in fundraising programmes. CCO tends to draw on the sympathy of the public. Donors present gifts in cash or kind to the home. The home has a visible fundraising appeal as there is a captive symbol of forty four disabled people needing care and assistance. This picture draws on the sympathy of the public. Visitors like foreign dignitaries will make official visits which receive wide publicity in the media. Once again the personal tragedy model of disability is highlighted. Disabled people are made to play the role of helpless people needing the charity of others. While funds are raised a price is paid at the expense of disabled people. This approach further stereotypes the dependency approach and portrays disabled people in a negative light.

SHO on the other hand makes no public show of members receiving assistance. No photos are taken when grants or wheel chairs are given. The assistance is delivered directly to the member concerned. While it has a house which serves as its administrative centre it does not have any images which will draw the public sympathy as the CCO would. SHO has been highlighted in press reports through highlights of their members. Two of the service users were featured in the media concerning their achievements at work. They made reference to the assistance provided by SHO. In this case the disabled person was portrayed in positive light as running a successful business. SHO does an annual fund raising appeal to private firms with an appeal letter and writes about its work in supporting members. The wording reveals their orientation:

Our members do not want to depend on charity. They want to be self-supporting, to have families, to live as normally as they can. But most of them are poor, and their poverty holds them down. They need only a little help to break themselves free and become independent- but they need it badly and they need it now. (Leaflet)

Other aspects of the write up highlight the types of service provided which enable the members to become self-supporting. One drawback in the printed leaflet is the type of photos used. Of the nine colour photos six portray their impairments and the aids provided. Three others highlight assistance in business, involvement in sports and a public gathering. This shows how a self-help group like SHO can be caught up in drawing on the sympathy of the givers. SHO in response to the researcher's comment has indicated that in the next year's appeal amendments will be made to better reflect the true image of SHO in the choice of photos.

2.2.4 Change possibilities

The key question is what will enable a change from the current understanding and approach towards one that is closer to the social model. In the case of CCO the process is more difficult as the people in high places do not take the time to be better exposed to the changing situations. For the past thirty years they have not been challenged in their approach. The Department of Social Welfare has given them a clear endorsement of their service. There are however some seeds of change which if nurtured over time might result in significant changes. Three trends could be identified. Firstly, CCO's role in developing a community based approach to reach every disabled person in the community is timely. This could spark a change for those in the home. In this context if some of the residents are directly in this programme it could provide them the experience for other changes to come. Secondly, the possibility of setting up a resident's self-reliance committee is another step forward. Although the proposal does not go far enough it must be seen as a first step in a series of stages enabling the residents to take control. The first step of having a Council member as Chairperson was suggested by the residents as they felt that a

committee chaired by them in the current situation will not make an impact with the council. Furthermore an open, direct confrontation will not prove useful and the residents themselves are not ready for it. Thirdly, the CCO International charter which emphasises the opportunity of disabled people to take an effective part at every level in running the services can assist this process. It is essential to popularise the charter among both to Council members and residents, encouraging them to study its practical implications for the running of the home.

SHO already operates within the social model and therefore is ahead of CCO in enhancing the rights and equal opportunities of its members. However SHO too needs to develop grass root structures in order to educate and mobilise its membership from being passive to become an active force within Malaysian society. For SHO this is an easier process as a number of their leaders are active in the national disability movement, as well as being linked with the Disabled People's International (DPI). The brainstorming discussion on employment-related matters is a clear indication of the possibility of quick adoption of changes within the organisation. With more internal educational and leadership programmes, SHO will in the future mobilise its grass-roots for a greater impact in communities nationwide. One clear way forward for SHO is the development of State Branches with the responsibility to recruit members in the state, raise funds as well as organise the direct case work programmes. This will enable the national committee to be involved in policy development, advocacy, leadership development and networking with other national bodies. SHO would be wise in the long run to develop branches in every district as the most manageable geographical area for a grass root committee to operate.

3. COMPARATIVE ANALYSIS OF THE APPROACHES

At the end of Chapter Six a four-fold typology of voluntary organisations was developed which have relevance for the Malaysian context. For the purposes of critical analysis each type has been identified separately, however in practice there is much over-lap as most of the organisations would be operating a number of different types within one organisation or have dimensions which might overlap between different approaches. In this section we will firstly analyse the approaches and seek to understand the dynamic of operations within the Malaysian voluntary sector. Secondly, we will attempt to reformulate the approaches and identify possible trends and developments for the future.

3.1 Approaches and the Dynamics of Operations.

What emerges clearly is that 'organisations for' tend to fall between the charity and enabling care approach whereas 'organisations of' are self-help and advocacy oriented. However there are times when 'organisations for' have also played an active part in advocacy or even facilitated the setting up of a self-help group. What can be noted is the transitory nature of some of the organisations. This means that in the case studies there are indicators of a shift from charity towards enabling and advocacy. In the case of self-help groups they are developing a stronger role in public awareness and policy advocacy. In setting the agenda within the voluntary sector some 'organisations for' are adopting conceptual and strategic plans as well as developing closer collaboration with disabled people. Unfortunately in the Klang valley there are no indications that 'organisations for' are opening up membership to disabled people and thereby ensuring that at least 50% of the elected officials are disabled people. Some disabled people especially among the visually impaired are frustrated with their self help groups and are working towards the

setting up of a new organisation which will have advocacy at the major priority. In the case of physically disabled people, a new self-help organisations have been set up by disabled people with spinal injuries. This organisation provides alternative models and opportunities for disabled people in the Klang valley region beyond the SHO which was analysed in Chapter Eight.

What emerges clearly from the field study are the drastic differences between the charity and self-help approaches especially when we compare them on the basis of the individual and social model of disability namely the orientation and impact of the charity tradition on the one hand and the mutual aid and self help tradition on the other. The charity orientation brings to light two images. On the one hand there is a positive aspect of human kindness and compassion which is tapped. This brings to light human nature that is loving and seeking to share with others, as the givers of care. On the other hand there is the image of the receivers, in this case disabled people who are seen as helpless and hopeless, in desperate need of assistance. There is an impact of this image on the individuals. In the case of the givers it is a positive sense of feeling good as well as public recognition of the service provided. The individual's image is enhanced. However in the case of the receivers there is a negative impact although their human need is met, it does not enhance their personal sense of worth nor social standing in the community at large. This is because they are seen as passive recipients of charity. The mutual aid and self-help traditions on the other hand are built on the basis of the potential of the affected individual and community to organise themselves and address the issues, challenges and needs they face in joint action. They might do this on their own or seek to work with others in partnership and collaboration. They have a higher sense of personal worth and are recognised by the wider

community in positive light as they do not project themselves as hopeless and helpless. They are not seen as passive but active in addressing the social issues and problems that confront them. Direct participation, involvement and control are elements of empowerment which is reflected in the citizenship model of social work practice.

We will develop this theme more fully by critically examining social work practice, voluntary organisations and the citizenship theme in noting how they fare in the charity care (CC) and self-help (SH) divide. In so doing we will seek to draw out major themes discussed in Chapter Two and Three. Table 13 provides a helpful summary of the critical points.

Table 13 : Critical Points between CC and SH

	CHARITY CARE	SELF-HELP
CITIZENSHIP OF DISABLED PEOPLE	Excluded Passive	Included Active
SOCIAL WORK	Individual model Disempowerment	Social model Empowerment
VOLUNTARY ORGANISATIONS	'Organisation for' Isolation	'Organisation of' Integration

3.1.1 Citizenship

The conceptual discussion of citizenship has tremendous relevance to this discussion. Unfortunately the major focus of academic discussions among political philosophers and

welfare theorists has been on macro issues which were discussed in Chapter Two. However the application of the citizenship principle is underdeveloped. An attempt to do this is made by Peter Beresford and Suzy Croft (1993) in using citizenship principles for community work. While their work gives pointers for practice they are weak on the conceptual framework. In Chapter Ten a critical assessment of this vacuum and the problem of developing adequate linkages between citizenship theory and practice is provided. Citizenship exposes the inclusion and exclusion principle. The charity approach further alienates disadvantaged people from mainstream society by isolating them from other citizens and denying them equal access to available resources. SH addresses this by working out an alternative by fostering collective support. The SHO discussed in Chapter Eight draws some variations from other traditional SH. This is because SH should draw on the mutual support of those involved whereby contributions come from within. However the SHO example is similar to the experience of CC in that it appeals to the general public for donations and then allocates what is received to those in need from within the SHO. Unlike CCs, SHO involves the users in the decision making process and the dominant decision makers are also disabled people. However in the SHO model those in the committee although being disabled people are themselves not recipients. They represented the well-to-do members from within the disability community. Class, gender and racial differences could be a barrier within the disability movement.

Central to the concerns of disabled people is the active - passive role. We noted this divide in Chapter Two as highlighted by Turner (1990). Non-disabled people are called to play a part as active citizens. An implication of being an active citizen for non-disabled people is, playing a part in fostering a caring society especially to unfortunate individuals in

society. While CC is an expression of active citizenship of one section of the community, it does create a passive role for disabled people. SH generally promotes the active role of its membership. However even within SH many disabled people do not seem to be active for reasons explained in Chapter Eight.

3.1.2 Social Work Theory and Practice

Earlier we established that the dominant understanding of disability falls either within the individual or the social model of disability. In the case of the CC it is clearly an individual focus in contrast with that of the SH which falls within the social model. Without doubt disabled people identify their difficulties from a wider perspective, taking into account their difficulties in education, employment, housing, and transportation related matters. Dina Faud (1991) captures the perceptions of disabled people in a Malaysian workshop when she notes,

from the perspective of the disabled themselves, the issue is a far-reaching one which goes beyond their inability to see, hear or move about freely. The message is clear and indicative of the sheer ignorance and prejudice to which they are often subject. Disability itself is not the issue, they [referring to disabled people at the workshop] suggest, rather it is their inability to exercise a certain amount of freedom and independence due to an environment which gives little consideration to the rights of the disabled. (Faud, 1991)

Many 'organisations for' also address these issues but often seek to address them by creating public awareness and facilitating policy input by working from within the policy formulation process. Details on the strategies for policy advocacy namely working from within or from outside will be discussed in Chapter Ten. However a majority of the 'organisations for' are seeking to provide specialised services. Here we can note that due to the limitations of voluntary organisations their target numbers are small and the enabling

and empowering in which they engage is more individualistic rather than developing a mutual aid or collective/activist approach..

Central to social work theory and practice is empowerment and there is a constant reminder and challenge from disabled people to non-disabled people to address the issue of power and control, namely 'who is in control?'. This could refer to micro concerns such as personal assistance or macro concerns related to education or employment policies. Empowerment means that disabled people have a direct role in analysing the issues as well as being involved in the decision making process. Matters related to dependency and independence as well as caring for and caring about have to be confronted. Whether it is in industrial or newly industrial countries CC's are oriented towards disempowerment rather than empowerment. Very often when the phrase is used there might be the tendency to provide 'lip service' as it is currently the right political language in social work.

3.1.3 Voluntary Organisations

CCs are 'organisations for' and their dominant focus is in doing good to others. This altruistic spirit is not wrong in itself. There are many well meaning people within the voluntary organisations whose potential should be tapped for the *common good*. This could be done with appropriate public awareness, and policies addressing altruistic or voluntary spirit from a social model of disability rather than an individual one.. Many 'organisations of' have non-disabled people who have worked closely with them for the empowerment of disabled people. A further dimension is the theme of isolation and integration. CCOs' dominant approach tends to isolate disabled people from the common avenues which other citizens use. Noor Hayati (1991) in describing the Malaysian situation says :

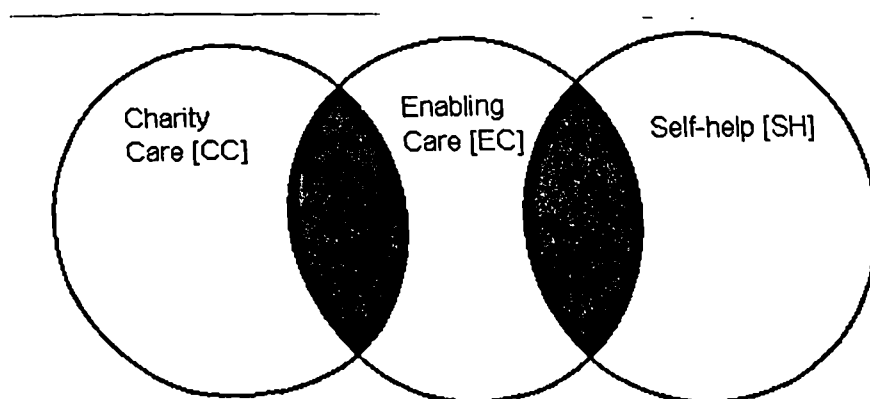
The handicapped of Malaysia feel excluded from the mainstream of society and they say they do not enjoy the same rights as every other able-bodied citizen. And this rejection persists despite their large numbers. (Hayati, 1991:30)

It is important to note that enabling care supporters are strong advocates of integration as they seek to open up the community for disabled people. This clearly means accessibility not just to physical premises but to all areas.

3.2 Reformulating the Approaches -Trends and Developments

Figure 11 illustrates the overlapping nature of the different approaches. What is being developed is a three-fold model namely charity care(CC), enabling care(EC) and self-help(SH) rather than the four-fold classification developed in Chapter Six. The approach which is dropped is advocacy. The reason for this is, the three other approaches each at some point involved an advocacy role. Advocacy ranges from individual to collective action, and from personal concerns to group and national issues. It was clearly pointed out in Chapter Six that SHOs' and ECOs' are involved in advocacy. It is therefore better to categorise advocacy as a feature within EC and SH rather than a separate approach. Furthermore the only organisation that defined itself in advocacy terms is in reality an enabling care organisation as disabled people are not in the leadership nor membership of the organisation.

Figure 11 : Overlapping Model



CC and SH are dominant approaches, whereas enabling care can be regarded as a transitional phase due to the overlapping nature of the approaches. Enabling care shares with charity in some features while in others it shares with SH. We can therefore note the links with CC and EC and EC and SH. However CC and SH are very different. In Chapter Four we noted the reasons for the emergence of self help organisations in Malaysia, with blind people taking the lead. One major reason which sparked the developments among blind people who received assistance from EC was their exclusion from the decision making process. When they failed to gain access into membership they formed their own organisations. There is a similar trend among hearing impaired people where the disabled people's movement *grew out of a EC to become a SH. In both these examples the 'organisations for'* were providing educational and training services with the view of enabling disabled people and providing opportunities to them. But did not create the mechanisms for their involvement in the decision making process.

There is a potential for a progressive movement of CCs towards EC and EC towards SH as illustrated in Figure 12. This is not only indicative of the Malaysian experience but the possible future course of developments. It is highly improbable that disabled people in a CC based organisation as described in Chapter Seven will establish a SH due to the Malaysian cultural dynamics and their passivity as a result of institutionalisation. However users of other services, for example Community Based Rehabilitation (CBR), would have a higher probability of reorganising themselves into a self-help group if the non-disabled people failed to incorporate them into the decision making process. While CBR has been able to tap the potential of the local community and families for active involvement it has not usually increased the involvement of disabled people. None of the 'organisations of'

are involved in this new development, while some disabled people employed as staff in Malaysian Association for the Blind have been playing a leading role in developing community based services for blind people. It is therefore important that SHOs attempt to influence ECOs towards this direction and members from within SHOs who are more affluent could play an active role in both CCOs and ECOs with the objective of challenging them towards SH.

ECOs have played a key role in developing SH among parents and family members. In the United Kingdom this is referred to as the Carers Associations. The CC on the other hand feels threatened by active parents and relatives as well as by active disabled people. ECOs tend to work closer with the families. While ECOs seek to enable disabled people they do not seem to be aggressive in the formation of SHOs. It is disabled people themselves who have taken the active lead in this process. However disabled people might have had the support of individuals from the non-disabled professional community but not from the CCs or ECO. In Chapter Six we noted the example of the YMCA while they have given greater involvement of disabled people in the management of the centre, they have not sought to form it as an independent organisations out of the YMCA. Furthermore it was members of the YMCA centre who set up the Kuala Lumpur Society of the Deaf. A similar situation can be noted in the Spastic Children's Association where ex-users are organised as a unit within rather than as a separate organisation, as a number of disabled people wished. The disabled people agreed to the request of the Spastic Council not to register themselves as a separate organisation. In return disabled people can operate from within the Spastic centre and make use of the resources. Greater freedom was given to them in organising their programmes. The disabled people in this case accepted the offer as they had difficulties in

fund raising. These examples reveal the true nature of most voluntary organisations namely protecting their respective 'turf'. Another reason could be that the presence of an alternative organisation could be a potential competitor in fundraising.

The self-help movement in Malaysia has the potential of developing into activist grassroots movements within the democratic framework of Malaysia as illustrated in Figure 13. This implies that SHOs become more localised groups operating within the local community as well as breaking away from the traditional medical categories. Another step in this direction is the need for them to move beyond the welfare circles. Currently when disability is discussed it is associated with social welfare programmes. However due to the role played by a number of individual disabled people, seeds have been sown for addressing disability in wider society. One clear example is in a document entitled Malaysian Charter on Human Rights by Malaysian NGOs (Suram, 1994), there is a section on 'people with disabilities'. In the past human rights groups in Malaysia focused on matters affecting *political* detention, gender concerns, factory workers, environmental and urban poverty groups. Therefore an inclusion of disability as a human rights issue is a step forward in the conceptualisation of disability in Malaysian society. A critical analysis of this is provided in Chapter Ten. While individual disabled people were involved in the drafting of the charter, none of the SHOs have endorsed the charter. The only Klang Valley disability organisation to endorse it was Dignity and Services. Another positive indicator in Malaysian society is the new column in a leading daily entitled 'Wheel Power' and a disabled person is the columnist and is playing a role in popularising disability related issues through the print media.

Figure 12 : Towards Self-help



Figure 13 : Between Enabling and Activism



While noting this possibility of the future development of activist grassroots movements, there is also the danger that increasingly the SHs might shift closer to EC through the provision of individualised services (see Figure 13). Politically this is more acceptable than an activist approach. Furthermore with the Malaysian governments role in popularising the caring society theme disabled people might compromise their role.

4. Chapter Conclusion

In this comparative analysis a three-fold typology of organisations has emerged as characterising of the Malaysian experience. This serves as a useful tool to understand the nature of voluntary organisations and the way services are organised. We have noted that the key indicator in line with the citizenship model of social work practice is the direct involvement of disabled people and their empowerment. Whether it is at the micro level of individual personal assistance or at the macro level of national disability concerns, disabled people must be in control of the process and outcome of matters that affect them.

In Malaysian society the SH model and approach has not been given enough attention. Disabled people in SH have not challenged existing inappropriate approaches but have provided direct assistance to members who have benefited from it. Discussions at the conceptual level and comparative studies have not been developed in the Malaysian context. Even the Malaysian Confederation of the Disabled have not challenged voluntary organisations to adopt a social model. This could largely be due to two factors. Firstly, Malaysians tend to be non-confrontational and not really expressing how they feel. Rather the general approach is coping within the framework or at best patiently seeking to change it slowly over time. While SHOs have played the advocacy role in obtaining provisions

from the government, they have not adequately challenged the inappropriate services of voluntary organisations or the public sector. One must remember, that those leading the 'organisations for' most often are highly placed people in Malaysian society and challenging them might not be seen as acceptable. Secondly, as there are so few services organised for disabled people, any assistance provided is welcomed. The pragmatic consideration in a realistic context is lack of services, provisions and choices. This could be the main reason why inappropriate and disempowering approaches are not really challenged in Malaysian society.

Noting that change will take time, the disability movement in Malaysia needs to draw upon the resources of both disabled people and non-disabled people in creating a new agenda.

Three areas essential for this process are:

Firstly, there needs to be more national level awareness programmes challenging the attitudinal and structural barriers that enslave and oppress disabled people in the Malaysian society. The mass media which have played a part in the past must be enlisted to assist in this process.

Secondly, there must be the development of a larger leadership pool of disabled people with appropriate training and experience to develop the movement. Potential disabled leaders must be identified from the grass roots in order to take the movement ahead into the twenty first century.

Thirdly, a strategy and action plan needs to be developed in charting out areas and courses of action to promote equal opportunities for disabled people in Malaysian society in areas such as education, employment and developing a barrier free society.

CITIZENSHIP MODEL OF SOCIAL WORK

1. Chapter Introduction

The time has now come for us to reformulate the citizenship model of social work practice which will be the focus of this chapter. The model was first developed in an outline form at the end of a critical review of citizenship and disability theories and their practical implications in Chapter Three. It has served as the basis for the enquiry into social work practice among disabled people in the Malaysian context from a citizenship perspective as analysed from Chapters Six to Nine. We have noted the usefulness of this model as a tool for comparative analysis of different approaches (charity care, enabling care and self-help) to social work practice in voluntary organisations in the Klang valley. The model likewise has been informed by the field study and therefore needs reformulation, taking into account the gaps and additional dimensions which were not taken into account prior to the field study and input from the Malaysian experience.

A contextual approach has been adopted. Midgley (1981) refers to this as the 'principle of indigenisation', meaning that "professional social work must be appropriate to the needs of different countries" (Midgley:1981:170). In a similar way, contextual, *means taking the local context to determine interpretation and application*. This is an important principle to recognise namely contextual and cultural specific requirements in seeking to implement a plan of action to facilitate changes. This approach is in keeping with the central ethos of citizenship which is not imposing from 'above' but rather facilitating input from 'below'. The Malaysian context as seen and experienced by Malaysians has informed the reformulations of the model for practice as described in this chapter.

While many of the general principles have relevance at a universal level, there are dimensions which are specific to the Malaysian context only, especially at the implementation level and might not be appropriate for another context, for example developed countries. It is, however, possible to imply that this reformulated model might have relevance for application in other newly industrialising countries of Asia which share a similar development in social policies and provisions for disabled people.

The reformulated model is divided into four parts with twenty-five guidelines. The first part on citizenship contains nine foundational guidelines. The second part on social work focuses attention on the appropriate theory and practice, which is comparable with the citizenship ethos namely social model of disability and a social development framework. There are six guidelines in this section. Policy, programme and structure are the focus of part three and four with specific reference to 'organisations of' and 'organisations for'. Ten agency guidelines provide a helpful summary of the model.

There is a balance emphasis on macro and micro concerns. The macro aspect is often neglected in the attempt to provide micro level services at the local level. Michael Edwards and David Hulme (1992 : 13), correctly notes this failure to make the right linkages between the micro level and the wider systems and structures. They further reveal that NGOs struggle for greater impact.

Small-scale NGO projects by themselves will never be enough to secure lasting improvements in the lives of poor people. Yet what else can NGOs do, and how can they increase their development impact without losing their traditional flexibility, value base and effectiveness at the local level. (Edwards and Hulme, 1992 : 14).

In this chapter we will seek to establish a balanced approach between the macro and the micro, between national policy and implementation at the grass roots as well as the scaling up of projects to ensure maximum impact. The citizenship model for social work practice as reformulated in this chapter takes these aspects into consideration. Therefore macro concerns are discussed not just to serve as the policy context for practice but an essential area for voluntary sector direct involvement. The attempt to define policy, structure and programmes along a two-pronged approach, namely ‘organisations of’ and ‘organisations for’, is consistent with preceding chapters which have revealed their major differences.

In Chapter Six and later in Chapter Nine we explored the role self-help groups were beginning to play in speaking up on issues affecting disabled people. Therefore in this Chapter we are acknowledging the place of self-help groups and note how they can be further strengthened through the adoption of a citizenship model for social involvement. This does not imply the demise of ‘organisations for’ but these too are challenged to reformulate organisational policy and structure in order to share power with disabled people. We have already noted positive examples and trends to this effect. Furthermore, the Malaysian experience of disabled people and non-disabled people networking and working together both at the macro and micro levels can serve as a model for similar partnerships in other contexts.

2. DISABLED PEOPLE AND CITIZENSHIP

Disabled people in Malaysia can make a claim for membership and inclusion into Malaysian society through citizenship rights and responsibilities. The potential of citizenship was confirmed through the literature review (Chapters Two to Four) as well as

the field study findings (Chapters Six to Nine). We noted that citizenship rights and responsibilities as described in the Federal Constitution were the basis upon which the Federation of Malaya was established on August 31, 1957. While citizenship was a relatively new concept, introduced into Malaya in 1946 after the Second World War, nonetheless it was the basis by which non-indigenous people like migrant Chinese and Indians who came to Malaya for work during the British colonial period received membership into Malaysian society.

There are clear instances in Malaysian society where disabled people have begun to analyse their place in Malaysian society making direct reference to citizenship. This is especially so in a number of national gatherings where disabled people have presented papers and have taken the lead in reviewing public policy on disability in Malaysian society. Bathmavathi Krishnan (*et al*, 1989), made one of the first links between disability and citizenship in the social policy discussions, stating that basic rights are meaningless if they cannot be exercised. John Kim (1991, 1995) identifies disabled people as second-class citizens, inferior citizens and "treated as lesser people" (John Kim, 1991 : 9). This analysis is based on the exclusion of disabled people from the general development of the country as experienced by the rest of Malaysian society. Sazali Shaari (1994) makes a similar claim for disabled people noting that the time has now come especially in the context of the prosperity which Malaysia is experiencing, that disabled people should also receive a fair share of society's wealth and opportunities. Shaari (1994) pointed out that disabled people are "discriminated against" and affirms that disabled people today "do not want to be left behind".

Anthony Thanasayan (1995b) compared the living experience of disabled people in modern Malaysia with the stone age. Commenting on the Malaysian Prime Minister's recent announcement of Malaysians now living in a space age, Thanasayan points out:

But it won't take much for anybody deciding to take a trip around Kuala Lumpur, our nations capital, today to discover that people with disabilities are virtually living in a stone age. Even our mode of transportation which our country has invested much in for the science age is not willing to take us in. At this rate, whether or not there really is a light at the end of every tunnel, people with physical disabilities will now never know because they won't be on it. (Thanasayan, 1995b: 6)

Among some of the disabled people interviewed terms like 'red i.c people'¹ and 'underprivileged citizens' were used to describe their experience of being a Malaysian citizen. Ding, a disabled person, said during an interview:

"If we belong to the country we should be treated equally. Because we do not have opportunities we are like red i.c people."

Misbun another disabled person interviewed, described his situations as an underprivileged citizen. He said :

"Are disabled people given the same rights ?, does the government understand ? If government see then we get whatever other citizen get. As a Malay people I feel discriminated because of my disability. Something needs to be done".

The recently established Malaysian Spinal Injuries Association (MASIA) had taken the lead in facilitating disabled people's understanding of their citizenship rights and responsibilities through a recent seminar which they hosted entitled "Towards a society for all: Counting disabled

¹In Malaysia every one is issued with an identification card (i.c). Malaysian citizens have blue cards and non citizens for example permanent residents or a foreigner with a work permit are issued with a red card which implies you are not a full citizen. Disabled people who are Malaysian citizens are issued a blue card like other citizens. The imagery of the red card is used to illustrate the exclusion.

persons as citizens"². The gathering of a majority of disabled people served as a valuable platform for their conceptualisation and claim to full citizenship in Malaysian society. The Malaysian government was represented by the Minister for National Unity and Social Development and the Director General of the Department for Social Welfare who officiated at the official opening. This direct link with policy makers is a useful occasion not only in getting across the concerns of disabled people to government but also a good publicity occasion, as the gathering received good media coverage.

The seminar focused on two aspects. Firstly, there was a discussion on policies, namely, the lack of appropriate ones and secondly, the sharing of experiences of disabled people and their experience of being citizens. The organisers rightly used the Economic and Social Commission for Asia and the Pacific, 'Proclamation on the Full Participation and the Equality of People with Disabilities in the Asian and Pacific Region' which Malaysia is signatory to as the starting point for discussion. The proclamation makes two direct references to disabled people as citizens. The proclamation recognises the problem of exclusion of disabled people from mainstream society and advocates to a society for all. However the major drawback of the proclamation is that, it places the problem of exclusion at the level of negative social attitudes of non disabled people and thereby neglects the issue of institutionalised discrimination and injustice. In spite of this the proclamation has provided disabled people in Malaysia with a document that they can work on and use to promote greater public awareness of their demand that Malaysian society should be a society for all Malaysians, including disabled people. Disabled people at the gathering drew

²The seminar was held at Kuala Lumpur from December 13-14, 1996. The researcher was involved in providing input on the theme in the formative stages to Ms Bathamavathi Krishnan who was the organising committee Chairperson and the founding secretary of MASIA. Godfrey Ooi was also involved in presenting the keynote address. The researcher was invited to chair the first plenary session and deliver some concluding thoughts at the end of the seminar.

examples of discriminatory practices that they faced in society in education, employment, transportation and many day to day aspects of accessibility which non-disabled people in Malaysia take for granted.

Earlier in Chapter Three a number of principles with regard to citizenship rights and responsibilities were listed in an outline form. These five principles serve as foundations for practice which affirms the citizenship rights and responsibilities of disabled people.

Guideline One

Disabled people are fellow human beings who have inherent rights and dignity. By virtue of being human they share the same rights as fellow human beings and citizens of the nation.

Guideline Two

Disabled people have political, civil, social and economic rights as citizens of the nation.

Guideline Three

All injustice and oppression restricting their realisation of these goals must be removed. Disabled people are not to be discriminated against by virtue of their impairments.

Guideline Four

The rights based approach also affirms the duties and obligations of citizenship. In this context citizens with impairments will have opportunities to play their part in nation building.

Guideline Five

Due to the experience of discrimination, there is the crucial need for appropriate legislation, for the protection and enforcement of these rights. Constitutional inclusions as well as new legislation needs to be enacted in order to ensure the desired outcomes.

Guideline One rests on the foundation that citizens are fellow human beings. Muzaffar (1993) provides a clear understanding in general of this notion, whereas Godfrey Ooi (1995) applies this directly to disabled people.

Chandra Muzaffar (1993) developed this notion by stating that,

When we begin to appreciate the real meaning of this idea of 'humanity as a single family' we will find it intolerable that such a huge segment of the human family does not enjoy basic economic, social, cultural, political and civil rights. We will want to find out what the underlying causes are of this terrible injustice done to our brothers and sisters. We will seek to change social relationships, transform social structures in such a way that a more just and equal world emerges in which each and every human being exercises her rights and executes her responsibilities in consonance with her inherent human dignity (Muzaffar, 1993 : 16 & 17).

Godfrey Ooi appeals to the higher moral consciousness in human beings as citizens "so that life would have meaning and dignity for everyone" (1995 : 5). In a land like Malaysia which is rich in spiritual and religious traditions this appeal 'to the human being' has tremendous meaning and significance. Tan Chee Beng (1991:195) notes the process by which individual human beings learn to be human and that our spiritual traditions can play a crucial role in this process of value formation. Disabled people can tap this process and develop the appropriate consciousness that people with impairments are humans like everyone else. Society as a whole can be remodelled into this consciousness namely to be disabled does not mean to be less than human.

Spiritual traditions and world views must be taken seriously. This is because the content and meaning of rights and dignity for nations in the South cannot be drawn from abstract notions but needs to be based on universal moral and spiritual traditions. Miles (1995) rightly observes that,

at least 70% of global disability is experienced in countries and contexts upon which western ethics and philosophy impinge only peripherally. (Miles, 1995 : 50)

He goes further to say that

in the postmodern and pluralistic age, the existence of concepts and belief systems that differ radically from those conventional in western debate cannot continue to be ignored; nor, on the other hand, too hastily swallowed. (Miles, 1995:50)

Guideline Two emphasis the holistic dimension of citizenship rights. The language of rights tends to emphasis the civil and political over the social and economic. Both Misbun and Paul, disabled people who were interviewed during the course of the field study emphasise the urgent need for opportunities in the economic aspect. Misbun notes,

"Standard of living must be in par with others. If we are poor we can't contribute to the development in country. If we are recipients but for how long. People will say I've given you enough. Enough is enough. It's not proper that we still keep on receiving."

A similar emphasis is made by Paul,

"Civil and political important. Focus should be firstly on social and economic especially economic, key - money, job, place to stay".

When we consider the policy and practice implications we will discuss differing approaches adopted by wealth distributionist and wealth creationist through which people gain access to resources. It is also important to note that while Malaysians might face restrictions in the political realm, Malaysia is still a democracy and therefore provides some democratic space for policy input and political action. Disabled people and their allies must tap these opportunities.

Terms like injustice and oppression as listed out in Guideline Three are a little difficult. This is because some people in Malaysia describe their experience and the experience of other disabled people as discrimination. However others emphasise the aspect of ignorance on the part of non-disabled people. This aspect can be illustrated from data from documentary and interview data. On the one hand Misbun in the interview uses the term 'discriminated', Shaari (1994) likewise uses 'discrimination'. However, John Kim (1995) in describing prejudice and discrimination ascribes it to ignorance and negative attitudes, and "not through any conscious ill-intention" (1995 : 2). Malaysians might be conscious of politically correct language to use. A major break through in the usage of this term 'discrimination' was when a recent report from the National Social Welfare Council (NSWC, 1995 : 11) described the predicament of disabled people as one of being 'discriminated' against in the workplace. Guideline Three therefore is essential in the realisation of equal opportunities for disabled people in Malaysian society.

Guideline Four affirms the balanced position on rights and duties. Practical implications of this are clearly defined in the role disabled people can play both in their organisations and voluntary organisations in general. Guideline Five notes the need for legislation which will ensure protection for disabled people. The disabled people's movement in Malaysia, MCD (1992) has identified two priorities in this respect during the Asian and Pacific Decade of Disabled Persons (1993-2002). Firstly, they have set it as their task to get the Malaysian government to ratify the United Nations Declaration on the Rights of the Disabled. Secondly, to make significant progress towards bringing in a "Malaysians with Disabilities Act" before 2020, ensuring equal rights and opportunities and forbidding discrimination.

Esther Lim's (1995) emphasis on legislative measures further affirms the importance ascribed to legislation by disabled people. She notes:

To be charitable is seen as a positive trait in most cultures. However, it is often-even thought not always-unreliable in the long run and on a scale not large enough to achieve what is needed. It is legislative measures that can effectively protect the rights of persons with disabilities. It is through establishing the necessary legal basis so that other measures to assist the disabled could rely. (Lim, 1995:3)

Guideline Six on equal opportunities and Guideline Seven an integrated approach to national development planning serve as the guiding principles for National policies. These are applicable not just for disabled people but have the capacity to incorporate the demands of other disadvantaged groups.

Guideline Six

In accordance with rights of citizenship, disabled people must not be viewed as objects of charity but must be accorded rights to equal opportunities and equal share in the resources of the land. On account of this principle the services provided must be comprehensive and universal, meeting the needs of disabled people on the basis of citizenship rights.

Guideline Seven

Disability concerns must be incorporated into macro economic and social planning processes and national development programmes for example in education, employment, health, housing, transport policies. This approach will ensure that the rights of disabled people are taken into account in order that they too will benefit from economic growth and development rather than being sidelined.

The concept of a development policy at a national level is familiar to most Malaysians largely due to the introduction and implementation of the New Economic Policy in 1970. As we noted in Chapter Two, the Malay community was economically disadvantaged and this matter was at the heart of the negotiations during the drafting of the Federal Constitution. However it was only after the racial riots of 1969 that the Malaysian

government introduced the First Outline Perspective Plan (OPP1) and New Economic Policy (NEP) in 1970 for the period between 1971 - 1990. The NEP had a two pronged approach namely, eradicating poverty irrespective of race and secondly, restructuring society to reduce the identification of race with economic function. This social engineering process introduced a quota system in various areas for example admission to universities, equity ownership, employment and promotion in the public service. This programme was adopted for a twenty year period with the State playing an aggressive role on behalf of the Malay community on the basis of positive discrimination programmes. Jomo (1989) comments,

In view of the economic deprivation of the Malay community historically, some positive discrimination and affirmative action is inevitable, especially since nominal Malay political hegemony has been assured since the late colonial period (Jomo, 1989 : 15)

At the end of the twenty year period there was much discussion on the positive and negative effects of the NEP period and the future policy to be adopted (Jomo, 1989; MCA, 1991; MIC, 1992; Kua, 1993; Muzaffar, 1989). To facilitate a participatory process the government set up the National Economic Consultative Council (NECC) to receive feedback from a cross section of the Malaysian community on a policy beyond the year 1990. This was a multi-sector council with 150 nominated members with a retired Cabinet Minister as Chairperson. However when the names and organisations represented were revealed it was noted that disabled people and their organisations were not represented in this process nor social welfare based organisations in general. 131 disabled people together with 18 non disabled people issued a press statement on February 24, 1989 expressing their concern. The extract is from their letter:

The setting up of the NECC is indeed a laudable move. Representatives from the various sectors are given a chance to put forward their views and opinions in framing a new economic policy. However, one glaring omission needs to be brought

to the attention... We feel the need to be represented, being a minority and disadvantaged group... A majority of the disabled are unable to be independent because they have been fettered not by their physical attributes but by a lack of foresight in formulating policies catering for the disabled. (Memorandum, 1989 :24)

Seven voluntary organisations of which two were 'organisations of' jointly took the opportunity to facilitate a Workshop³ on the theme of equal opportunities and draft a Memorandum which was presented to the NECC. The workshop brought together over seventy participants a majority of whom were disabled people. Two members of the NECC took part in the plenary sessions and received feedback from disabled people. This experience has proved useful for a number of reasons. Firstly, disabled people were clearly making a claim for their inclusion into macro policy planning. While it is difficult to evaluate the impact nonetheless some concerns of disabled people have come to the forefront of policy discussion. Secondly, it has provided the confidence that disabled people can make a contribution to policy formulation at the macro levels. Thirdly, it was realised that allies were need in situations where direct representation is not possible for the time being. In the Malaysian experience, disabled people had to devote time to brief NECC members of their concerns. Fourthly, this experience has further enhanced the networking among 'organisations of' and 'organisations for' as there was collaboration in this process. Fifthly, it became clear that a more systematic way and organised structure for policy research and input is essential. This effort by the seven voluntary organisations was ad hoc. In the long run agencies like the Malaysian Confederation of the Disabled (MCD) should be better staffed to coordinate this process.

³ The researcher together with Bathamavathai Krishnan, Godfrey Ooi were members of the organising committee and drafting committee on the workshop findings refereed to as Memorandum (1989)

While the NECC report made a clear reference to the inclusion of disabled people, the final government policy entitled The Second Outline Perspective Plan (1991-2000) and the National Development Policy only made references to "disabled" in the context of developing a caring society. The focus was very much from the perspective of the provision of social welfare services "to enable the less fortunate to enjoy better standards of living" (Malaysia, 1991 : 153) .

In Malaysian disabled people are predominately viewed from a social welfare perspective. This is one possible reason why disabled people while they are among 'the poorest of the poor' in Malaysian society, are not categorised alongside poverty groups. This omission is reflected in all the major government policies (like the OPP1 & NEP as well as the OPP2 and the NDP) as well as major poverty studies in Malaysia (Mokhzani and Khoo, 1977; Zakaria, 1986). While poverty and the Malay community has been the major concern for policy analysis and implementation of poverty eradication programmes and other aspects like gender (Jamilah Ariffin, 1992, 1994), ethnic minorities (Ramachandran, 1994; Lim Hin Fui, 1994) and class (Jomo, 1986) are being taken into account, issues related to disability have still not emerged as a priority in poverty studies. Poverty studies in Malaysia are largely dominated by economists and disability concerns are not on their list of concerns, at least for the moment. Discussions related to disability tends to be relegated to the caring society and welfare, as well as health and medical forum where disabled people are seen more as recipients of care than as equal members of society.

The problem for disabled people in Malaysia is further complicated by the lack of data on poverty and disabled people. This is largely due to the way poverty is measured by

reference to a poverty line income and household sizes. (Malaysia, 1995). Data available from the Department of Statistics presents poverty within a household size of at least five people. Disability related aspects are not taken into account. Therefore the 1990 figures released indicating that 143,100 households or 4% of total households are hardcore poor (Malaysia, 1991 : 15), gave no indication whether disabled people were included in this number. The absence of adequate data will hinder appropriate action that needs to be taken. As the concerns of women and ethnic minorities are being taken into account in poverty studies likewise disability concerns must surface, if the concerns of disabled people are to appear on the drawing board for national planning and appropriate action. If this is not taken into account disability concerns will continue to be part of selective, special provisions for 'welfare dependents'.

There is therefore an urgent need to bring disability concerns within the wider national development planning in line with the equal opportunity policy. Among the fourteen interviewed in the final stage of the field study, nine affirmed that equal opportunities should be the focus and the other five indicated the need for a balance between equal opportunities and empowerment and charity and nursing care. While this is a small sample from the leadership in the voluntary sector it is indicative of the present state of informed opinion in Malaysia. While a majority want to see the implementation of equal opportunities others still see the need for specialised provision which is charity and nursing focused. There will always be this dynamic tension. However it is important to note that an equal opportunities approach will not be ignored for those who are more severely impaired. Ding an interviewee said, "we want equal opportunities as well as choice", Another disabled person interviewed, Timothy felt that the citizens model as described in

Chapter Three did not give enough emphasis to equal opportunities. Shati, a disabled person interviewed pointed out:

"Oh Yes, important to incorporate issues of disabled persons into national planning. You see, like women and youths, they have reference in Malaysian Plans. There must be change of attitude in government. They must treat us with priority".

Shati has indeed pointed out the need and has made an appropriate link with policy statements in National development planning about women and youths. In a similar way the disability concerns should be integrated into national planning as a whole rather than in a specialised way in the context of social welfare provision within the caring society framework.

Disabled people (Memorandum., 1989) argued along lines of positive discrimination. They noted that :

... where there are essential and rational differences between one person or group of persons and another, there may be differentiation in treatment of both. This means that one is required to treat only like cases alike. Neglect of the poor, weak and the disadvantaged by letting them to fend for themselves 'equally' with others who are powerful and have unimpeded access to full enjoyment of the resources for living a meaningful life is a travesty of justice. There is therefore a moral responsibility and, indeed, a legal duty, in a society committed to equality before the law, to ensure that disadvantaged persons or groups must be granted special protection of their rights to correct what would otherwise be unequal treatment of the disadvantaged. In this respect there is surely no group more deserving in the Malaysian context than the disabled. (Memorandum, 1989 : 3).

In chapter Two reference was to Young (1989)'s on 'differentiated citizenship', has relevance for our discussion here. Adopting such a policy in the post NEP period in Malaysia will give further meaning to the NDP policy which continues the NEP objective to eradicate poverty irrespective of race but shifts :

...the focus of the anti-poverty strategy towards eradication of hardcore poverty while at the same time reducing relative poverty (Malaysia, 1991 : 4)

Zainal Kling (1993) drawing on the Malaysian experience affirms group action. He points out:

In Malaysia at least group prominence is the social order compared to individual or personal dominance. It follows, therefore, that group action may be a better strategy for development as indicated by the idea of cooperatives or trust funds, or even productive circles. Group action structured by traditional hierarchy would certainly provide a ready made frame for action. But it goes against the modern idea of equality and equity. In this case, implementation of programme and distribution of wealth could take the form of a challenging task of cultural modification from traditional inequality by way of equitable distribution or the often quoted idea of positive discrimination. (Kling, 1993:16).

Therefore the emphasis of Guideline Six in this section draws upon this rich heritage of equal opportunities and affirmative action which is incorporated into the national development planning. The focus in Guideline Seven is upon integrating disability concerns into all other specific national policies namely education, employment, health, housing, transporting rather than making disability concerns just a special concern which in reality tends to be relegated into welfare provisions rather than being part of mainstream policies.

A further implication of this framework is that, like other citizens who turn to a cross section of government agencies for support likewise disabled people should not be isolated with one government agency. This point was well argued by disabled people in Malaysia:

The various government ministries and departments in Malaysia cater for the needs of various sections of the Malaysian population. However, in the case of the disabled, their needs are mainly catered for by the Ministry of Welfare Services. This approach rests upon the traditional assumptions that the needs of the disabled are a matter of charity rather than legitimate rights of people who are citizens. There is therefore a need to decentralise the programmes for the disabled to the relevant government ministries. Decentralisation means that the different needs of the disabled are met by respective ministries. (Memorandum, 1989 : 5)

In identifying this policy, specific reference is made to how different government ministries and agencies like health, education, labour (human resources), youth and sports, housing

and local government and welfare should be involved in supporting disabled people as full citizens of Malaysia.

There are two positive indicators that reveal a change by which disability concerns might in the future be incorporated into national social development policies. In a recent government report on poverty eradication (Malaysia, 1995) disabled people were identified as one of the groups who might be either negatively affected or have failed to benefit from the economic growth and modernisation. This document cites the National Welfare Policy and notes that

in dealing with social problems, curative and rehabilitative approaches alone will not be sufficient. They have to be complemented by preventive and development strategies as well. (Malaysia, 1995 : 31)

We have earlier in Chapter Four noted the contents, strengths and short comings of the National Social Welfare Policy. This attempt by the Malaysian government to recognise disabled people as one among other poverty groups is a step forward. The National Social Welfare Policy which contains an orientation towards equal opportunity has the potential for building upon it. While specific details and targets for social development were not provided in the recent government report (Malaysia, 1995) in comparison to the other poverty groups nonetheless it can serve as a useful starting point for disabled people to make a claim for appropriate inclusion in development planning. There is an urgent task in Malaysian society for disabled people and their allies to seize these openings in policy statements and give the relevant meaning and context and thereby influence policy makers towards disability concerns.

A second positive trend is found in the resolutions of a recent social development seminar⁴. It was resolved that the National Social Welfare Council consider changing its name from social welfare to social development in order to reflect the changes in orientation and approach. A task force was set up to draw up guidelines to assist member voluntary organisations adopt a social development strategy in line with the World Summit for Social Development declaration.

While it is too early to conclude that a major change in approach and orientation will develop, there are undoubtedly positive trends which disabled people can utilise to achieve significant advances. These can serve as starting points not just of more effective policy analysis but also of political analysis and strategy.

Thus far we have emphasised the principles and policies that are essential to a citizenship model of social work. In stating them we have also in certain instances indicated practical implications. In this part what is developed are two national plans. Guideline Eight, affirms welfare pluralism as a strategy plan through which disabled people will receive services from a variety of sources. This leads us to develop further details of 'organisations for' and 'organisations of'. In the earlier model of Chapter Three no such distinction was made, however as a result of the field study findings as noted in Chapters Six to Nine, the differences as seen in priorities, services and approach have further necessitated drawing out separate guidelines for policy, programmes and structure as revealed in the third and fourth sections. (See Table 14). Guideline Nine explores possibilities for direct involvement

⁴ The seminar entitled Malaysia after Copenhagen was organised by the National Social Welfare Council from Sept. 18 & 19, 1995. The researcher was a participant as well as appointed to the Task Force to study the resolutions for implementation.

in the policy and implementation process moving beyond the welfare framework for implementation.

Guideline Eight

While the State is to ensure and safeguard the citizenship rights of disabled people, a plurality of service providers is needed in order to consolidate the position of disabled people in main stream society namely the role played by the public sector and the self-help, alongside voluntary, informal and private sectors.

Guideline Nine

Consistent with citizenship responsibility, disabled people will be encouraged to play a part in development and appropriate democratic mechanisms will be utilised at the national, state, district and local levels.

The basic strategy of Guideline Eight is welfare pluralism. There continues to be a positive tension between the different sectors especially the state and voluntary sectors with regards to the balance in service provision. David Green (1993) writes about the 'crowding out' effect of the welfare state and how the voluntary associations have been squeezed out. He affirms that "much of what we call the welfare state should be returned to civil society" (1993 : 152). On the other hand Marjorie Mayo (1994), while recognising the place of the non-public sectors, states that

there is no way in which the voluntary sector, self-help or community initiatives can realistically substitute for the mainstream of public provisions and resourcing. (1994 : 196).

Herein lies the tension. The citizenship model of social involvement as developed in this chapter recognises the role the state must take but at times it is essential that other sectors especially the self-help sector receive adequate support in order for disabled people to take the lead in realising their citizenship in Malaysian society.

We noted in Chapter Four that welfare pluralism was the adopted principle in Malaysia since the late 1940s. A similar emphasis is affirmed through this principle with a key role assigned to self-help organisations. Neil Gilbert and Barbara Gilbert (1989) referred to the state as 'an enabling state' in the context of western capitalism where there is a "division of responsibility in the financing and delivery of social provisions" (1989 : 4). More recently Gerald Hales (1996) edited work dwells on the notion of 'an enabling society' where the notion of support to disabled people extends from a handful of experts to a wider community response with disabled people playing a key part. A similar emphasis has been made in policy discussions in Malaysia (Jayasooria, 1993a, 1994e).

It is important to note the unique role of the Enabling State. Seven points with regard to the role of the State was developed in an earlier account is outlined here.

Firstly, to ensure the basic rights of disadvantaged persons (i.e. education, employment, housing, social/public amenities and transport) are protected and provided for, through the enactment and effective enforcement of legislation.

Secondly, to set up mechanisms for co ordination of services, setting standards, monitoring and evaluation. In this way the State likewise is responsible for macro-level planning.

Thirdly in organising and developing training programmes for personnel in social work is essential and needful. The voluntary sector will not be able to invest funds in this very important task of equipping the workers both paid and voluntary.

Fourthly, along with training it is necessary to create public awareness through the mass media. The media has been playing an important role in this and much more could be done in providing programmes which will mobilize people for action as well as educated in changing false attitudes. The media can play a constructive role in preventive education.

Fifthly it is essential for the State to give due recognition to all the sectors and include them as legitimate partners by setting up mechanisms that will promote consultation in the decision making process.

Sixthly, the State must justly allocate funds/grants for public, voluntary, informal and self-help sectors.

The State should devote attention or finance social research and publications as a seventh role.

Finally, the State should cease to provide direct services but purchase them from the other four sectors. This will enable them to play an effective role to evaluate the effectiveness of the services provided. (Jayasooria, 1994e : 6)

The State needs to play the enabling role and in so doing sets the stage for the other sectors to play their part, which facilitates the development of an enabling society. As John Clark rightly notes "the poor rarely benefit from economic growth unless there are government policies to ensure that they do" (Clark 1991 : 25). This is one of the reasons why we have focused so much attention in this chapter on national policy and also the role of the State in this process. The Citizenship model developed in this Chapter further devotes attention to self-help groups and the voluntary sector. However it does affirm that all the sectors should play their part in enabling disabled people to realise their full citizenship.

Guideline Nine on democratic mechanisms for people participation in development is also important. While there are opportunities through the electoral process for participation through party politics there are however numerous other opportunities at the National, State, District and local levels for participation in development. Thus far disabled people and voluntary organisations have participated directly in welfare based and service matters which have direct relevance to disabled people. If there are opportunities for representation it would be on an advisory council of disability and not in a general forum like the NECC. Disability concerns must become part of general discussion alongside other national and local concerns. MCD rightly identified this as a crucial need and have identified the appointment of disabled people to

decision making bodies such as the Senate and local authorities. (MCD, 1992). The Senate in Malaysia is the Upper House in Parliament and is served by appointed members representing political parties, cultural groups and minority groups. While a Senator does not hold power within the Parliamentary system he or she can influence the policy process from within government.

The local authority system could be very useful if disabled people could be appointed, it could make a significant contribution to integrating disability concerns in the local community alongside other community issues and concerns. Since 1963 local government elections have been suspended and councillors are appointed. Phang Siew Nooi (1991) study looks at women's participation in local authorities which according to her is male dominated. With regard to appointments she points out that the:

appointment of councillors is through a process of political bargaining within the component party and a person has to be prominent to be recognised and nominated. (Phang, 1991 : 44)

Tan Boon Kean and Bishan Singh (1994) reveal the appointment of representatives from consumer associations to Municipal Councils in two different States. They note that this success was because they adopted a complementary rather than confrontational approach. In a similar way, Michael who is another disabled person interviewed said

"Disability action is political action but disability as a political issue is a safe issue. Only issue, is when you join other political and human rights groups which are anti-government, if the group is seen as linked with opposition political parties".

Malaysians' will not be able to escape this reality and would need to work within the democratic space and political climate in order to effect changes to the benefit of disabled people. Disabled people and their organisations must begin to network with agencies beyond the welfare and health concerns and at the same time be cautious not to be branded as anti-government. In taking a middle way for the moment and breaking out of the welfare circles, the concerns of disabled people will be addressed beyond the welfare discussions and agencies. Misbun makes a helpful comment :

"Disabled people should join normal networks like Rakan Muda (youth movement), consumer and cooperatives. Disabled people need to be contributive citizens, members of society. Must move beyond the disability problem. In so doing society will understand us".

3. DISABLED PEOPLE AND SOCIAL WORK

Thus far we have sought to focus on foundational principles based on citizenship which have implications for national policy and implementation. Fundamental to this for practice is finding an appropriate theory to serve as a base for practice. In the Citizenship model developed at the end of Chapter Three, we linked social work and the social model of disability within citizenship. In the reformulation an attempt is made to link citizenship, the social model with a social development approach to social work practice.

Currently in national development planning, economic and social considerations, as indicated in earlier sections are the dominant concerns for planners. Therefore it is appropriate to locate disability concerns in this approach and thereby seek a greater integration of disability concerns with mainstream society.

It is envisaged that Malaysia by the year 2020 will be a developed or industrial nation. This approach to development is not just in the economic sense and the Malaysian Prime Minister qualifies it:

By the year 2020, Malaysia can be a united nation, with a confident Malaysian society, infused by strong moral and ethical values, living in a society that is democratic, liberal and tolerant, caring, economically just and equitable, progressive and prosperous, and in full possession of an economy that is competitive, dynamic, robust and resilient. (Mohamad, 1991 : 2).

It is appropriate to place disability concerns within this agenda of Vision 2020 and Malaysia becoming an advanced industrial country by that year. Locating disability within the social model and social development will enable the integration of disability concerns not only at the policy and practice level, but also at the macro and micro levels.

Three theories (Guideline Ten, Eleven and Twelve) are integral to the citizenship model of social work practice. They are interrelated and a helpful guide to practice. Guideline Ten centres on the social model of disability which was clearly described in Chapter Three. Disability is placed beyond the individual level. It is in line with our earlier policy statements on equal opportunities and integrating disability concerns into the wider policy and national context. Guideline Eleven reemphasises different dimensions of development which is related to the different elements of citizenship rights. Guideline Twelve focuses attention on empowerment and the direct role of disabled people in bringing about change at the macro and micro levels.

Guideline Ten

The citizenship model of social work can only be built upon the social theory of disability, as disability is not an individual problem based on the personal tragedy theory. The social oppression faced by disabled people due to the disabling environment must not only be seriously taken into account in developing social intervention programmes but must be the focal point of action at the national, state, district and local levels.

Guideline Eleven

The development that is envisioned for all Malaysians including disabled people is holistic, which is not just welfare but includes economic, political, social, spiritual, psychological and cultural dimensions. Different dimensions are incorporated. It is people-centred as people are the central focus of development.

Guideline Twelve

Empowerment is enabling disabled people to take control. It is a process which enables disabled people to explore the extent of their potential and overcome the limitations set by negative attitudes of society. It is primarily enabling and enhancing the capacity of people to determine their own future.

Guidelines Ten, Eleven and Twelve are inter-related. The appropriate orientation as emphasised in Guideline Eleven is a holistic and people centred vision of development where the concerns of disabled people are not viewed from an individual theory but on a social model. The effect of this is the empowerment of disabled people to take control and play a major role in their claim for inclusion into mainstream society, not as passive recipients but active in determining their own future.

As emphasised a holistic orientation is one in which there is a balanced emphasis on the difference dimensions of development including the economic and social. A key feature is the theme of human development where the various dimensions of being human are taken into account namely intellectual, physical, physiological, spiritual,

social and sexual. Disabled people alongside other disadvantaged groups and communities do not have adequate opportunities for holistic development as human beings.

John Clark (1991) indicates that development in its broadest sense means improving the society. It is basically 'enabling people to achieve their aspirations'. He further notes that it is enabling rather than providing. This approach reflects the true character of development, that is development by the people and not to the people. David Korten (1990), likewise challenges us to an alternative vision of development. He directs our attention towards a people centred vision, that is enabling and enhancing the capacity of the people to determine their own future. This is why Korten (1990) views development as a people's movement. Korten (1995 : 179) lays strong emphasis on using local resources and making these accountable to the people through strong member-accountable institutions.

The Manila Declaration on Social Development (ESCAP, 1991) calls on the governments to ensure

that social development concerns receive appropriate consideration at the highest levels of government *through their full integration* into overall development policy, planning and programming and regular review by all concerned agencies and organisations (ESCAP, 1991b : 30)

The emphasis is upon a comprehensive, integrated and sustained policy, planning and programming response to provide for improvement in the quality of life for all the people. In a similar way Malaysia has sought to place a balance between economic growth and social well being. This is reflected in official policies and frequent

references made in political speeches. In the words of the Malaysian Prime Minister "we want to achieve a balanced material and spiritual development without losing our own good values"(Mohamad, 1992). It is therefore essential for disabled people to remind politicians regarding their policy statements and concepts used in their speeches.

The earlier model developed at the end of Chapter Three represented a balanced approach recognising the place for case work, group work and community work. However, in this reformulated model community work is emphasised for a number of reasons. Firstly, the reformulated citizenship model addresses disability concerns from a macro to micro, rather than a micro to macro approach. This is consistent with the social model which shifts the focus from the individual to the disabling environment. These matters were more fully discussed in Chapter Three. Secondly, adopting a community based approach does not mean that individual concerns and needs of disabled people at the micro level will be ignored. Micro and individual concerns will be addressed through peer group support and support workers but these provisions will be directly under the control of disabled people. This was clearly illustrated from the in depth case study of the self-help group in Malaysia as analysed in Chapter Eight and Nine. While adopting a group approach, the self-help group placed a lot of emphasis on enabling individual members from being either institutionalised in a residential centre or in their home in the local community. Thirdly, a community based approach draws support from other sectors but ensures that the programmes are under the control of local democratically accountable agencies. Fourthly, the problem many local groups have faced when starting from the micro is that they have found

it difficult to make the shift to the macro as they are tied down to the little details at the micro level. Furthermore, lacking a clear picture of the macro, these micro-focused organisations often tend to be caught up in providing inappropriate services using inappropriate approaches.

Fifthly as Tan Ngoh Tiong (1995) rightly observes there is a contextual reason for the preference for a community approach.

Asian social work tends to be more community focused especially social work in rural settings. Prevention and development strategies need to be systematically incorporated in social work intervention. For example intervention approaches involving 'gotong royong' or community self-help, mediation of conflicts using indigenous leaders, 'kong-si' or mutual aid associations amongst clan or ethnic groups, would more effectively take into account cultural differences in intervention and be more acceptable. (Tan, 1995 : 5)

For the above five reasons a community based approach is adopted. As indicated in Chapter Three and Chapter Four, community based rehabilitation (CBR) is seeing expansion in the Malaysian context. In Malaysia self-help groups have not played a key role within this. However as we noted in Chapter Three, Peter Coleridge (1993) refers to experience in other developing countries to demonstrate the potential role of disabled peoples self-help groups in community based rehabilitation.

Guideline Thirteen

A comparable practice model with the citizenship model for social involvement is community work, where the focus is upon working with disabled people as a group or community of people addressing both national and local issues, macro and micro concerns.

Guideline Fourteen

The community worker serves as a resource worker, facilitator, and enabler working alongside and in collaboration with disabled people rather than one who is in control and an expert.

Guideline Thirteen and Fourteen is based on a community based approach. Community work is pro-active in orientation and seeks the mobilisation of affected people to play a key part. In Chapter Three we also focused on the principles formulated by Peter Beresford and Suzy Croft (1993) which inform the emphasis here on a community based approach. Anil Bhatt (1995) highlights the dimension of community mobilization which both throws light on the potential of community work and gives us a picture of the role of the community worker in this process. Bhatt (1995 : 83) indicates that this process involves capacity building, self-reliance, participation and empowerment. These are the very same terms and concepts we have noted in the citizenship model developed in this chapter. Bhatt's explanation of the basic principle is helpful for our discussion:

The basic principle behind this approach is that unless and until people themselves become capable and active, development cannot take place. People are not perceived as passive recipients who accept whatever benefits and services are given to them, but rather as active participants who make demands on the delivery systems. In the mobilization role, the major activities are providing information, education and training, developing awareness and conscientization, imparting various skills, and forming formal or informal organisations of the people themselves. (Anil Bhatt, 1995 : 83).

In adopting a citizenship model, social workers knowledge and skills, as well as their training programmes need further review. Midgley (1981) provides some helpful pointers in social workers acquiring appropriate skills for involvement in a social development framework. He points out that the workers:

will require technical skills...[in]...a wide range of new subjects such as development economics, demography, social development, statistics and the skills of computer programming, data processing, cost-benefit analysis, budgetary planning, operations research and other techniques. (Midgley, 1981:149).

The further implication is that the team of workers working alongside disabled people will also need to include other professionals in law, business development, town planning, architecture etc. rather than the traditional team of medical professionals.

In the conclusion of Chapter Three we noted two options that disabled people in Malaysia had in order to realise equal opportunities in Malaysian society. One approach enhances participation, group solidarity and collective action through the political process. In this approach VOICE is central where disabled people have a voice for direct action to claim their rights in society. Furthermore it is an approach which seeks to lobby the government to provide services and resources through wealth distributionist approaches like income support and grants. The second option is through CHOICE where the market provides and disabled people tap into the wealth which is being created. In the citizenship model developed in this chapter both these approaches are seen as valid approaches and disabled people in Malaysia must attempt through their self-help groups to tap into whatever democratic space is available and at the same time ensure their place in the market in order to benefit from the growing prosperity of Malaysian society. It is important to note that both (VOICE AND CHOICE) are dependent on each other. In order to ensure a place in the market, disabled people need to use their voice through the democratic mechanisms to ensure that they are not left out of the opportunity to create wealth. If disabled people are not careful they might end up with residual welfare handouts through State or voluntary

provisions if they only sought to make claims through wealth distribution approaches. However in keeping with the equal opportunity policy discussed in the earlier section, disabled people must use their VOICE to ensure their CHOICE, to enter or exit opportunities.

Guideline Fifteen

In keeping with social development a plurality of programmes could be adopted, utilizing both state and market options in order to ensure there is adequate opportunity for disabled people in Malaysia to have a share of the resources of the land. Therefore wealth distribution and wealth creation options are available to disabled people.

With regards to the democratic space and opportunity in this context, we have discussed these aspects in Chapter Four as well as more fully in the earlier section. Let me reaffirm five important points we have already discussed. Firstly, disabled people must tap into the available democratic space in Malaysia. Secondly, they should not restrict themselves within welfare based discussions *only but must integrate* disability concerns through all available channels and networks at the national and local levels. Thirdly, we have noticed that in Malaysia the media have been good allies to disabled people, especially in drawing public awareness to the disabling environment. However disabled people must devote time and energy to ensure that views expressed are in the interest of disabled people and truly creating an enabling society. There are times when wrong images and inappropriate concepts are propagated because of journalists ignorance. Fourthly, to seek inclusion into public policy formulating bodies like the Senate and policy forums like the NECC. And finally for appointment in implementing agencies at the local level like Local Authorities.

The potential of the markets with regards to wealth creation and disabled people was discussed in Chapters Seven, Eight and Nine. The self-help group especially saw the potential of disabled people in small business in the Malaysian context and provided support in order to ensure success. The intention is to enable disabled people to tap into the business opportunities in the market place. What many of the disabled people did not have was the capital to start or expand their business. The banks and financial institutions saw them as a credit risk. They did not have the collateral needed to secure loans and therefore had no access to the formal banking institutions.

There are now very well documented accounts of the poor in general, who through small loans for their small business have lifted themselves out of poverty (Gibbions and Kasim, 1990; Joe Remenyi, 1991; Getubig *et al.*, 1993, Thapa *et al.*, 1992; Conroy, 1995). Similarly some disabled people have been successful in micro enterprises (Jayasooria, 1994d, 1995b).

Gibbion and Kasim's (1990) findings from their work among the rural poor Malays have lessons for disabled people who are among the poorest in Malaysia. They noted that there were two categories among the poor. The first category had no adequate opportunity and therefore needed more than credit. They also needed motivation and skill development. In the case of the second category all they needed was a loan to pull themselves and their families out of extreme poverty. These have parallels for us. Among disabled people there are those who want to start a business but do not have the skills as well as funds, and there are others who are struggling due to lack of

credit for expansion. Small businesses provide an option for disabled people to break from the poverty cycle.

Voluntary agencies can also play a part in ensuring that disabled people have a share in the community enterprises set up. In Chapter Seven we noted examples of business projects owned by the voluntary organisation. Other examples are similar projects like sheltered workshops where disabled people are wage earners. In a majority of these cases the disabled people are very poorly paid and they tend to have a low self image in comparison to disabled people who own the business (Jayasooria, 1994d, 1995b). Many of these projects are run in unbusiness like ways and therefore, fail to tap the business potential of disabled people. Voluntary agencies therefore need to review their projects in order to tap into the potential of the market as well as to ensure that disabled people's business opportunities are enhanced through profit sharing and joint-ownership schemes. Business should be run business-like for profit, rather than as a subsidized venture.

A recent International Labour Organisation (ILO) study provides, some positive indicators with regards to self-employment for disabled people:

Self-employment has often proven successful for people with disabilities. The advantage is that they can undertake the tasks for which they have the aptitude and competence at a pace compatible with their disability. As self-employed people usually work in or near their home, problems of travel and mobility are reduced. (ILO, 1994 : 15).

However the ILO (1994) report also observed that the failure rate in such small businesses might be higher than non-disabled people. The difficulties faced by members of the self-help organisation studied in Chapter Eight was taken seriously by

the SHO. In the feedback provided by the researcher to the SHO during the course of the field study, the leaders of the self-help group met a number of times to discuss some of the difficulties. They also have charted ways in which they can provide mutual support to fellow members in small businesses. Failure can be minimised if appropriate support is provided by self-help, voluntary organisations and the public sector.

It is important to note that these small business are not looking for subsidies but an opportunity like the businesses of non-disabled people. In the Malaysian context while the Department of Social Welfare officers provide assistance to small businesses *and* grants as indicated in Chapter Four, the small businesses run by non-disabled people receives professional support through a newly created government agency called the Ministry of Entrepreneurial Development. Here is where disabled people and their organisations must exercise their VOICE to ensure that their small businesses are not treated as welfare cases but as potential businesses to sustain the economic growth of the country and be integrated alongside similar categories of small businesses.

4. DISABLED PEOPLE AND ‘ORGANISATIONS OF’

The fifteen guidelines discussed above can serve as foundational for self-help organisation’s social work practice at their macro and micro levels. Five agency guidelines are provided for implementation and divided into three sections dealing with agency policy, programmes and structures. (See Table 14)

4.1 Agency Policy

Earlier, in Chapter Three, we noted the role played by ESCAP, the UN regional office, in promoting the development of self-help groups of disabled people in developing countries. In a helpful manual (UN, 1993c), prepared to serve as a guideline, the place and need for democratically elected and accountable organisations is affirmed. This principle serves as the basic premise for the development of 'organisations of' at the National, State, District and Local levels in Malaysia. Agency Guideline One draws attention to the specific role that self-help organisations need to develop disability concerns on the national agenda.

Agency Guideline One

Recognising the important role self-help organisations play, there is a need for disabled people and their organisations to set the national agenda for disability policy and services in Malaysia by drawing together all appropriate groups, agencies and networks in Malaysia using citizenship and social development framework.

In the Malaysian context, the MCD and its member organisations should continue to take the existing positive openings in Malaysian policy discussions further by developing well formulated policies in line with the VISION 2020 and the NDP. In so doing set the agenda for the incorporation of disability concerns into mainstream policy formulation and implementation. This is urgently needed and the MCD as the democratically representative organisation of disabled people must take the lead. In this process they should not seek to isolate but to involve other key players by drawing on their resources and expertise.

Table 14 Implementation of Citizenship model for social work practice in voluntary organisations

	'ORGANISATIONS OF'	'ORGANISATIONS FOR'
POLICY	Setting the agenda for disability policy and services in Malaysia	Adopting a social model and social development orientation by resetting organisational vision, objectives, services and structure
PROGRAMME	Setting up new services based on social model Grass-roots mobilisation Scaling up programmes	Recruit disabled people for direct involvement Develop support services Scaling up programmes
STRUCTURE	Create mechanisms for greater involvement of disabled people	Create mechanisms for disabled people's direct involvement

There is an urgent need for disabled people and their allies to draw on existing policy statements in Malaysia, along with the UN and ESCAP documents, in order to formulate a comprehensive and integrated policy. This could be used to lobby government and call for its adoption. Appropriate monitoring processes also need to be developed to ensure effective implementation.

4.2 Agency Programmes

Programmes and projects are an essential part of setting a new agenda and direction for disability work in Malaysia. Three programmes are emphasised in this section. Agency Guideline Two, points out the urgent need for self-help organisations to set up and run alternative services based on the social model. We have noted in Chapter Six, that it is the 'organisations for' which are key providers of services like day care, residential, educational, and vocational training programmes. The time has come for disabled people to run alternative service models which are based on the social model and accountable to disabled people themselves. Agency Guideline Three draws reference to scaling-up the programmes. One major problem of voluntary action as we will note later is the weakness of organising small projects which make very little impact because they reach only a very small clientele of disabled people. Agency Guideline Four draws attention to the development of disabled people from self-help groups towards a grass-roots movement of disabled people.

Agency Guideline Two

In line with the social model of disability, self-help groups should creatively set up and run new services which are accountable to disabled people. The objective is not only to provide appropriate services but also to challenge inappropriate models in the Malaysian context.

Agency Guideline Three

Past experience shows that small scale services and programmes lacked impact at the National level and they catered for a small number of disabled people to the neglect of a majority of disabled people in Malaysia. Therefore appropriate programmes need to be developed with the view of replication and scaling up operations in order to serve the maximum number of disabled people in Malaysia.

Agency Guideline Four

While MCD plays an important role in representing disabled people, however the reality is that a majority of disabled people in Malaysia are isolated in their home and unknown, and far from being members of self-help groups. There is an urgent need to identify all disabled people in Malaysia and encourage and enable them to join or establish self-help groups. In so doing to facilitate the shift from self-help groups of disabled people to grass-roots mobilisation of disabled people in Malaysia as a people's movement.

The analysis of the structured interviews on Social Work Practice (Appendix 9) at the macro level, reveals some interesting findings. In response to the question about urgent tasks thirteen of the fourteen interviewed indicated the following four out of the ten targets as most urgent by ranking them one or two. These are not listed out in order of priority but in the order they appear in the questionnaire.

- Organising disabled people into self-help or self-advocacy groups
- Educating and training disabled people
- Employment opportunities
- Public awareness on rights and potential of disabled people

These can serve as the key priority list for not only 'organisations of' but also 'organisations for'. The latter will be discussed in the next section. Misbun one of the interviewees in this study, captures the situation disabled people are in and he calls for action in addressing the issues faced by disabled people. Misbun said:

"Disabled people do not respond because they are not well equipped. Many don't know even to read. There is low-self esteem, inferiority. They also lack communication skills. Need to develop human potential. Can gain this through motivational talks".

Timothy another disabled person interviewed, also identifies some specific aspects :

What I would like is, of course the first thing is to mobilise and, as we have already talked in the past, at the present time our leaders want to do everything and seem to be supreme, so what we should do is to delegate as much as we can to those who have been given the authority. And then, next we should appreciate what each leader has done. This recognition and appreciation factor is missing.

Ding another disabled person makes a comment on the role of the disability movement drawing out the relationship between service providing and advocacy.

"Yes, they [referring to disabled people's organisations] have to be service-providers. On the rehabilitation side, they must also try to think of ways and means to rehabilitate their members and, policy level, that is also very important that we have to work together with the government to change. And we have to also tell public the needs that we want because a lot of people want to help but they don't know how to help. So we have to promote them with a lot of public awareness and tell them that this is our need, this is what we want, this is what we can do. We have to project ourselves".

Disabled people's organisations in Malaysia should seek to explore different service models. There is a need models for alternative models to residential services. In Chapter Three we noted the potential of the Independent Living Movement (ILM) and the liberation it has provided for disabled people especially in the US. Later in Chapter Four it was pointed out that group homes for people with learning difficulties were a step in the direction of ILM alternative to residential care. There is a need and place for disabled people's organisations in Malaysia to study this model and popularise it in Malaysia by also seeking to find adequate funding for its effective implementation.

Earlier we also noted that disabled people's organisations had not explored the potential of community based rehabilitation. Therefore in Malaysia when public funds are being allocated to expand services to disabled people in the community, disabled

people and their organisations should use this opportunity to tap into such funds particularly to set an alternative model for practice where disabled people are playing a key role in planning, analysing social needs, decision making, implementation, monitoring and evaluating the services being provided.

It is in this context as Agency Guideline Three highlights, that there is a need for a systematic plan in expanding services to provide as many disabled people as possible with appropriate services. The services provided in Malaysia are inadequate. Wayne Tomlinson and David Gibbions (1995) provide some helpful pointers in writing about scaling projects in poverty eradication. They highlight firstly, the horizontal scaling-up which is an expansion from one project to many, in other words, replication in other places. The advantage is the ability to reach more but the difficulty is the funding and personnel needed for the expansion. Secondly, vertical expansion which is the increase of service users and members within existing programmes. The advantage is concentration on one project but the draw back is while the project is well run it reaches a smaller number of people. Based on their experience of the Grameen⁵ replication models, Tomlinson and Gibbions advocate vertical scaling up. This is because they see the consolidation of one effective programme first for a short period as the basis for replication in the long run.

⁵ The Grameen project which first began in Bangladesh was started by Prof. Muhammad Yunus in 1976 is a Non-Governmental programme which has demonstrated that the poor are bankable and that the poor can play a key part in working their way out of poverty through small business. It is a credit delivery programme for the poor and has evolved into one of the world's biggest banking institutions for the poor. (Getubig *et.al*, 1993)

The membership restriction by the SHO was discussed in Chapter Six and Chapter Eight. There is a need for MCD to organise a review of strategies adopted. This is because one goal of the self-help organisations should be to expand their activities in order to reach as many disabled people as possible in the country.

Linked to the idea of scaling up operations is the notion of seeing the transformation of self-help groups into a movement of disabled people. This aspect is emphasised in Agency Guideline Four. Some have attempted to link the disability movement as a social movement (Richard Scotch, 1988, 1989; Diane Driedger, 1989, Michael Oliver, 1990, 1996; Rene Gadacz, 1995). The emphasis placed in this chapter with regards to this theme, centres on the notion of reaching the maximum number of disabled people in Malaysia who are now isolated in their homes and not part of self-help groups, and on the fact that disabled people are moving out of a passive role into an active one in playing a part in the political process by bringing to the surface disability concerns beyond the welfare framework.

4.3 Agency Structure

If the policies and programmes discussed in the earlier sections are to be established it will be necessary to review organisational structures to establish whether the current structures will facilitate change or restrict it. In the earlier Citizenship model it was suggested that agencies should develop structures based on small, decentralised, democratic units to maximise participation and empowerment. These principles are reemphasised in the reformulated model in the light of the field study findings as reflected in Agency Guideline Five.

Agency Guideline Five

To create appropriate organisational structures to enable maximum participation of members in planning, decision making, service provision, resource allocation and evaluation. It is to establish democratically accountable organisations.

In the Malaysian context there is one umbrella co-ordinating organisation of disabled people namely the MCD which represents disabled people who are members of four national self-help organisations. There is a need to enlarge this at the National, State, District and Local levels and MCD should facilitate this movement. Currently its role is restricted by lack of personnel, funds and a vision to see the disability movement as a grass roots movement representative of a majority of disabled people in Malaysia. MCD has potential and should work out and establish the means to enlarge its representation.

5. DISABLED PEOPLE AND 'ORGANISATIONS FOR'

In Chapter Four and Chapter Six it was noted that 'organisations for' are a major provider of services to disabled people and that these organisations have not really promoted the direct involvement of disabled people in membership, elective office, staff positions and the direct provision of services (assessment, planning, intervention, decision making, resource allocation and evaluation). This is largely because voluntary organisations have been operating on an inappropriate model of social work practice. The Citizenship model for social work provides new possibilities for voluntary organisations. The focus however in this section is how 'organisations for' largely controlled and led by non-disabled people could become more accountable to disabled people through the democratic process. A voluntary organisation is normally registered

as a society with the Registrar of Societies. There is a constitution, open membership, and governing council elected by and accountable to the membership. A majority restrict their membership and tightly controlled by narrow unrepresented councils.

The fifteen guidelines provides framework for an 'organisation for' to adopt agency policy, programmes and structures which will provide greater control and be more accountable to disabled people and local communities. Five agency guidelines providers useful pointers for implementation. (See Table 14)

5.1 Agency Policy

The starting point for organisational change is agency policy. This is the first step as emphasised by Agency Guideline One. While this process will not be achieved overnight, nonetheless a start could to be made. As indicated in the earlier, the National Social Welfare Council is adopting a social development strategy, this could be useful in giving support to the organisational change that is needed. This council with the support of MCD could develop clear guidelines for the change based on a social model of disability. Earlier in Chapter Nine we noted the possibilities of voluntary organisations making a shift from charity care to enabling care and be modeled closely to self-help. In this section we will explore this more fully.

Agency Guideline One

Voluntary organisations are urged to adopt a social model of service provision and therefore need to reformulate organisational vision, objectives, services and structure to reflect a social development orientation

The key issue is how do we get voluntary organisations to adopt a social model. Public awareness and education is the key step. Many agencies have taken the medical

and tragedy model for granted because they think that this is how services for disabled people should be run. Therefore the policies developed by the UN and ESCAP should be translated into simple guidelines for implementation and adaptation for practice. The social model is gaining influence in academic settings and its influence in staff training is likewise important. In due time a new generation of professionals, among whom will be disabled people, will lead the way forward. Developing alternative models based on the social model is another step. Disabled people and their organisations should facilitate workshops on this shift, encourage and challenge, voluntary organisations to adopt more appropriate models which are more effective in meeting the needs of disabled people. Voluntary organisations as a membership will need to work through vision, objectives, services and structure to ensure that it is consistent with the social model. In so doing not to neglect individual concerns.

5.2 Agency Programmes

For voluntary organisations which accept the difference and aim to make changes, the way forward is firstly, to organise a training programme for non-disabled people based on the social model of disability. Resource people are available in the self-help groups to facilitate this process. Secondly, the organisation can adopt a membership recruitment drive and provide training opportunities for disabled people on matters related to organisational management and related issues. In the following three guidelines different aspects related to programmes are mentioned.

Agency Guideline Two

In line with the social model of disability, voluntary organisations must encourage, recruit and train disabled people for membership, elected office and staff employment. Some targets and time frame should be adopted to establish and evaluate this.

Agency Guideline Three

Voluntary organisations could develop support services to facilitate the formation and expansion of self-help organisations at the national, state, district and local levels.

Agency Guideline Four

In order to reach a majority of disabled people in Malaysia voluntary organisations need to evaluate their current operations with the view to expanding operations.

Voluntary organisations based on Agency Guideline Two will also need to develop targets for recruitment and a time-frame. This is done to ensure that disabled people are really incorporated rather than have a policy change without specific results. It must be noted that in this process every effort must be made to avoid tokenism. There must be a genuine effort on the part of non-disabled people to share power and the organisation with service users and disabled people in general. Specific attention must be given to inclusion of disabled people in elected and staff positions. With regards to staff positions in voluntary organisations, the job descriptions as well as interview procedures need to be rethought in order not to impose non-disabled people's perspectives. Specific targets like 50% in elected and staff positions could be set over a certain number of years. Self-help groups could be invited to serve as management consultants to voluntary organisations, as well as monitoring implementation.

Agency Guideline Three challenges voluntary organisations to develop support services to facilitate the development of self-help organisations. With a conceptual change based on the social model this is possible. Where voluntary organisations have resources like buildings they should make them available for self-help groups to function. Furthermore it would be appropriate to develop new support teams who can serve as barrier free or accessibility consultants. Other resource people like lawyers through legal aid or business consultant for small business will in due time break the dominance of traditional professionals based on health and welfare models. This does not mean that there is no place for health and welfare professionals. They still have their role within their expertise but based on the social model other resource people to also need play a role in areas where their support is urgently needed to ensure a barrier free and enabling society develops.

5.3 Agency Structure

Agency Guideline Five

Appropriate mechanisms need to be created through organisational constitution and structure to ensure opportunities for the direct involvement of disabled people in voluntary organisations.

While policies and programmes are important, however these efforts must be complemented by appropriate structural support. This is the emphasis of Agency Guideline Five. As it stands in Malaysia there are no requirements in the constitutions of voluntary organisations for the inclusion of disabled people. Technically no disabled person can be denied membership but in practice voluntary organisations dominated by non-disabled people have not encouraged an open membership policy. This is where an organisation might now introduce into its constitution a provision for the

inclusion of disabled people and even consider representation based on race and gender. Another alternative, practised by some voluntary organisations in Malaysia is not a constitutional provision but an understanding which is minuted and carried out. The latter is done in order to avoid legal and technical implications if the targets set cannot be met.

Smaller organisational structures at the local level where groups have some autonomy from centrally controlled national organisations could facilitate greater involvement. Localised groups could network with National based groups under an umbrella structure. In so doing the localised and small groups do not feel isolated but can be involved in any major National campaigns. In adopting this approach localised groups can attempt to create partnerships in working between disabled people and non-disabled people and also seek to develop services which cut across the traditional divides based on medical categories .

6. Chapter Conclusion

In this chapter we have reformulated the Citizenship model for social work practice which was first developed at the end of Chapter Three, after making an assessment of its value and applicability through the field study. Changes that needed to be made in the light of the field study and understanding of the Malaysian context have been made. In this process of reformulation three important aspects regarding the citizenship model can be summarised in conclusion.

Firstly, the model developed links the principles of citizenship with both the social model of disability and social development. In so doing it integrates disability concerns into national development planning of the country, thereby ensuring that disability issues and concerns escape the narrow confines of the welfare framework.

Secondly, the model establishes links between the macro and micro, between national policy and local practice, demonstrating that such links are imperative if disability concerns are to be effectively addressed and achieve maximum impact.

Thirdly, the model developed recognises the vital role which disabled people must play in their own empowerment and the importance of adequate resources being allocated to that purpose.

Vic Finkelstein and Ossie Stuart (1996) present proposals for developing new services which have many parallels with the model suggested here. One aspect that they emphasise is that services for disabled people must be developed outside the umbrella of special services and therefore outside a caring paradigm if the 'disabling culture' which currently dominates is to be broken. (Finkelstein and Stuart, 1996:172) Earlier in this chapter, it was pointed out that there is the need for disability concerns to break out of the health and welfare circle of service provision for disabled people and be fully incorporated in national planning.

The way forward for disabled people in Malaysia and elsewhere, is to lobby for inclusion in the services provided for all citizens. Those channels should also provide

the support needed for disabled people who are equal and full citizens of the land like any one else.

CONCLUSION

Throughout this thesis three aspects of social welfare have been addressed. Firstly, citizenship; secondly, disability theories and models; thirdly, disabled people and voluntary organisations in the Klang valley region of Malaysia. This final chapter provides a summary response to the research questions which were first identified in Chapter One and later in Chapter Five. In so doing an attempt is made to draw together the major findings of this study.

1. Major Findings

The central research question on the relevance of the current discussion of citizenship for social work practice among disabled people in Malaysia, was at the heart of the investigation. The eight subsidiary questions provided further specificity and each one of these is briefly answered in this section.

Firstly, on the issue of the relevance of citizenship for Malaysia in general, at the outset in Chapter Two after the review of citizenship discussions it was affirmed that while citizenship is relatively a new concept in Malaysia, it nonetheless was the basis upon which the independent nation of Malaya came into being on August 31, 1957. Furthermore it was noted that non-indigenous people received membership into Malaysian society on the basis of citizenship rights protected by the Federal Constitution. In response to Turner who said "citizenship appears to be historically and culturally specific to western culture" (Turner, 1993:176), the colonial experience of Malaysia reveals the contrary. While the focus of the citizenship discussions in Malaysia predominantly centres around ethnicity, it provides the

historical precedents for other neglected groups like disabled people to claim their inclusion on the basis of citizenship rights and responsibilities.

Turner (1993:182) also questioned the adequacy of citizenship to protect individuals against a repressive or authoritarian state and notes that human rights might be a more useful approach especially for non-western cultures. The language of human rights in most Asian countries is seen as politically sensitive, especially when western nations like the United States link trade to environmental, labour or human rights issues as well as the European Union's policy on conditionalities (Muzaffar, 1995). Therefore the current reaction of Asian governments to the imposition of human rights, the language of human rights, although appropriate, may not at this time be politically feasible in Malaysia. It is important to note that within citizenship, the language of rights is affirmed in balance with responsibility.

Turner's (1990) distinction between active and passive citizenship, achieved from above or from below, have proved useful in analysing disabled people's involvement both in understanding national policy or local service provision through voluntary organisations. Alongside this theme, the inclusion or exclusion from membership of society has been useful for review and discussion.

One major finding of this study is that disabled people in Malaysia can make a claim for their membership and inclusion in Malaysian society based on citizenship rights and responsibilities. It is also clear that consistent with citizenship principles, disabled people themselves and their organisations will have to continue to take this lead not only at the

level of analysis and advocacy but also in developing creative alternative services which afford disabled people ownership and control.

Secondly, on the question of individual and collective approaches within the framework of citizenship, this study has drawn upon both the Malaysian experience and the work of Young (1989) on special rights and group representation. The Malaysian experience reveals the place for group rights alongside individual rights. The Malaysian policies for affirmative action for socio-economically disadvantaged communities like the Malays and other indigenous communities, provides another precedent for collective action. There is the opportunity to make such a claim by moving beyond ethnic distinctions and thereby taking gender, age and impairment categories into account

Thirdly, in response to the question of the current position of disabled people in Malaysian society, the study clearly revealed that disabled people were recipients and targets of charitable caring. A majority of disabled people are disadvantaged and excluded from mainstream society whereas a majority of non-disabled people of Malaysia are not. This analysis is provided by leading disabled people in Malaysian society. The analysis of documentary evidence and interview data in a majority of chapters where the voices of Malaysian disabled people was heard supported their analysis.

Fourthly, disabled people and their organisations are making a claim for their inclusion. They have extended disability analysis beyond welfare and health concerns and draw attention to their exclusion from education, employment, housing, and transportation. In so doing they have adopted a social model (Oliver, 1983, 1990, 1996). This link between

citizenship and the social model was made early in this thesis. A citizenship model of social work practice was developed in Chapter Three and then finally reformulated in Chapter Ten. The latter model pulls together the major findings from the Malaysian experience and analysis by drawing out fifteen citizenship and social work guidelines for practice.

Fifthly, in making a claim for their inclusion in Malaysian society, disabled people like all Malaysians have to contend with the democratic space available in articulating their issues and concerns in society. The study shows that disabled people and their movement have adopted a non-confrontational approach with the State and society. Malaysians have operated on "the principle of accommodation" (Muzaffar, 1993a) and this provides an opportunity for disabled people to make a claim for inclusion just as non-indigenous groups like migrant Chinese and Indians did during the pre-independence period. Disabled people and their organisations, especially MCD, *are playing a direct part in this process* which, as they say, will take time to achieve the desired changes.

Malaysian disabled people are faced with a tension in this process and in Oliver's (1990, 1996) terms it is the tension between 'marginalisation and incorporation'. While it is important not to be marginalised from policy discussions, at the same time there must be a distance to avoid being incorporated into the system and thereby losing the advocacy role.

Finally, questions six, seven and eight centre on the theme of disabled people and voluntary organisations in the Klang valley. This study is an original piece of empirical research on voluntary organisations in the Klang valley. The citizenship model of social work practice

was the basis of this analysis. One key indicator of the citizenship model was the role played by disabled people in the voluntary organisations especially in areas such as holding elected office, membership, employment as staff, and in decision making. Throughout the thesis two types of organisations were contrasted namely 'organisations of' which are organisations directly set up and controlled by disabled people and 'organisations for' which are those by non-disabled people. The typology that emerged is significant and further has indicated the ideological position of the voluntary organisations.

The findings show that in 'organisations for', disabled people are predominantly passive recipients of charity and dependent for their welfare on others. While, in contrast, 'organisations of' facilitate direct and active participation of disabled people. However it was also noted that the Malaysian disability movement has not tapped the potential of a majority of their members nor are there attempts at grass-roots mobilisation. The reformulated citizenship model (Chapter Ten), provides pointers as to how both 'organisations for' and 'organisations of' could formulate organisational policies, programmes and structures which will facilitate greater participation of disabled people.

The field study also revealed the change in direction, largely advocated by disabled people, to incorporate disability concerns into national development planning and thereby foster greater integration of disabled people into Malaysian society. This would also involve mainstreaming through the normal channels experienced by other Malaysian citizens at the level of policy as well as implementation of services.

2. Methodological Considerations

The collaborative action research method especially 'the focus groups' provided the disabled people an opportunity to be involved both in the design of the research and in giving feedback on the analysis of data being gathered. This approach can serve as a valuable tool for non-disabled researchers to receive feedback on research design, interview questions and data analysis. It also calls the researcher to account to disabled people who have been subjects of the research.

The attempt to link macro and micro concerns, theory and practice, quantitative and qualitative approaches in one field study, is another potential for further development. In this research experience, the macro concerns of disabled people on national issues set the agenda for programme implementation at the micro level. Very often voluntary organisations start at the micro and build up towards the macro. However the right approach is to gather the macro picture and then from a bigger perspective, narrow it to specifics at the micro level. The study reveals that disabled people have adopted this approach.

One tension the researcher had in undertaking the field study was the tension of being an 'observer' who was involved and an 'activist' seeking to introduce the findings to the organisations with the possibilities of change for organisational policy and practice. This was especially so during the indepth field study. The researcher had to tread carefully especially in the CCO where revealing too much might jeopardise the good relations with the officials who had given permission to undertake the study and at the sametime lose the confidence of the residents of the Home. In the SHO there was greater openness to receive

feedback and a number of meetings were organised by the disabled people who finally drafted their report for their executive committee.

3. Areas for future research

In the course of this study the researcher noted the lack of research done on disability in Malaysian society. Four key areas are proposed for future research.

Firstly, an in depth study of disabled people in self-employment where they are tapping the potential of economic growth to discover the extent to which economic independence is empowering them in Malaysian society. The study could further examine the difficulties faced by disabled people in accessing the resources available in areas such as bank loans and in the development of their businesses.

Secondly, there is a need to study the role of *Local Authorities* in building a barrier free environment for disabled people. Thus far lobbying has addressed the Federal government. While this is important, little attempt has been made to get local authorities to implement national policies for example The Uniform by-laws. There are currently shortcomings in implementation and monitoring which no one is seriously taking into account. The study could look at the possible role of grass roots disability movements at the district level who can act as 'watch dog' committees.

Thirdly, gender and disabilities issues have not been adequately addressed. This area of double disadvantage needs study because disabled women in the Asian cultural context are more disadvantaged as compared to disabled men. Matters related to women's role and

expectations in the family and marriage might add further pressures on disabled women. Women's groups in Malaysia have not addressed the issues facing disabled women and an examination of this might reveal the attitudes of non disabled women. The matter might be further complicated if the issue of ethnicity is also taken into account.

Fourthly, there is a need to examine cultural, racial and religious differences and perspectives of disability. In a society where religion and race plays are important dimensions, an in depth study on these matters will further advance the cause of disabled people. There is a need to identify and explain cultural differences in the way different communities respond to disabled people. In particular, the question of whether, for example, the Malay community may be more prone to provide a *family support*, in contrast to the Chinese community, who might prefer to get the disabled person admitted into a residential setting needs to be addressed.

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Appendix 1

DIRECT SERVICE PROVIDING VOLUNTARY ORGANISATIONS

'Organisations OF'

Society of the Blind, Malaysia (SBM)
Tunanitra Welfare Association of the Blind
Pertis (Islamic association of the Blind)
Agape Christian Service for the Blind
Kuala Lumpur Society of the Deaf (KLSD)
Society of the Orthopaedically Handicapped (POCAM)
Society of the Chinese Disabled Persons in Malaysia
Welfare Association of Little People (Kerdil)
Association of and for Little People of Malaysia
REACH: Educating the Able-bodies and caring for the Handicapped

'Organisations FOR'

Malaysian Association for the Blind (MAB)
Selangor & F.T Society for the Deaf
YMCA Self Reliance Centre (Pusat Majudiri 'Y'
National Society for the Deaf
Society for the Rehabilitation of the Disabled, Selangor & F.T (PPOC)
Cheshire Home of Selangor
Selangor Association for the Retarded Children
Society for the Severely Mentally Handicapped
Malaysian CARE
Day Spring Day Training Centre
Kiwanis Downs' Syndrome Centre
Dignity and Services Bhd. (D&S)
Community Based Rehabilitation Co-ordinating committee of Gombak
Society for Families of People with Learning Difficulties(SFPLD)
St Paul's Day Training Centre
Pusat Kasih Sayang (YWCA Centre for women with disabilities)
National Autistic Society of Malaysia - Autistic Educational Centre
Spastic Children's Association
Tasputra Perkim
Bangsar Ria Day Training Centre
Asrama Cahaya

ORGANISATIONAL QUESTIONNAIRE

NAME OF ORGANISATION: _____

1. Background Information

1.1 Date of founding :

1.2 Founding members ,any disabled people ? Yes No
-if yes, how many and type of disability

1.3 Do you have a brief write up on your founding and historical overview Yes No
-if yes, please enclose a copy

1.4 Type of registration
- Registered as a society
-Registered as a company limited by guarantee
-any other, please clarify _____

1.5 Does your organisation have a write-up stating the goals/objectives of the services Yes No
-if yes, please enclose a copy

1.6 Does your organisation have a clear stand which affirms disabled peoples' position in society, on equal opportunities and integration in society Yes No
-if yes, please enclose a copy

1.7 Do you publish an annual report ? Yes No
-if yes, please enclose a copy of 1991, 92, 93 report

1.8 Does your organisation have a long term/ vision/ goal ? Yes No
-if yes, please enclose a copy

2. Type of service provided

Please state the services provided. If there are any leaflets describing your service, please enclose them.

3. Target group served

3.1 State the type of disability group served

Visually Impaired ()Hearing Impaired ()

Orthopaedically Handicapped () Learning difficulties ()
 Others () Please specify: _____

3.2 Numbers catered for

Age Group	Maximum Capacity	Current numbers	Waiting List
0 - 12 yrs			
13 - 20 yrs			
21 - 39 yrs			
40 & above			

4. Family / Community Based Services

- 4.1 Do you run/facilitate a client support group or social club ? Yes No
 - if yes, number of persons attending ? _____
 - how often do they meet? _____

Type of activities organised:

- 4.2 Do you run/facilitate a parent support group? Yes No
 -if yes, number of persons attending ? _____
 -how often do they meet ? _____

Type of activities organised:

5. Awareness

- 5.1 Does your organisation conduct public awareness/educational programmes ? (eg. public talks, gatherings) Yes No
 -if yes, describe nature and how often conducted

- 5.2 Has your organisation submitted any recommendations to the government, released press statements on the rights of disabled people or any related issue? Yes No
 - if yes, please enclose a copy of the recommendations/ memorandum/press release.

- 5.3 Does your organisation network with other organisations in organising public awareness and influencing public policy? Yes No
 - if yes, please state which organisations and on what occasions.

6. Involvement of Service Users

6.1 Parents/Family members

In what ways are family members involved in service provision ?

	Number Involved	How Often	Nature of Involvement
Elected office in the organisation			
Dialogue session with parents			
Provide input in planning & evaluation			
Others (specify)			

6.2 Disabled People using the service

In what ways are those receiving a service involved in the organisation ?

	Number Involved	How often	Nature of Involvement
Elected office in the organisation			
Dialogue sessions			
Provide input in planning & evaluation			
Others (specify)			

- 6.3 Does your organisation have a policy on the involvement of disabled people in the running of the organisation. Example: in holding office, in identification of needs, planning, allocation of resources and evaluation ?
-if yes, please enclose a copy of the policy.

Yes No

7. Personnel

7.1 Number of paid staff

Full Time Staff	
Part Time Staff	
Total	

Indicate number of disabled people employed as full time staff

7.2 Number of regular volunteers ?

8. Finance

What is your total income/expenditure for 1991, 1992, 1993 (projected) ?

	Income	Expenditure
1991		
1992		
1993		

Appendix 3

ORGANISATIONAL SEMI-STRUCTURED INTERVIEW QUESTIONS

1. Background information
Name
Age
Gender
Organisation
Duration of involvement in organisation
Marital status.
2. What made you join this area of work?
3. Did you have any initial fears as you started this area of work and how did you overcome this?
4. What is your current role?
5. How do you feel concerning the service provided ?
6. What problems have disabled people faced in using the service (or in general as a disabled people) and how has the organisation responded ?
7. In your analysis do you think the way the service is provided and the type of services are preparing disabled people to be independent ie economically (job security), place for stay and self confidence (personality development)
8. How do you get the involvement of disabled people in the services you provide and in the organisation ie in elected office, in planning and delivery of service?

What problems do you face in this process?
9. How do you get the involvement of parents and what problems do you face in this process?
10. If you had an opportunity to reorganise the service / organisation how and what would you do/change?
11. What in your opinion should be the role of the full time staff and volunteers?
12. What are some of your struggles in fulfilling your task?
13. In your opinion what do you think are the rights of disabled persons? Are they a reality in Malaysian society?

SERVICE USERS' CASE STUDY OUTLINE

1. BACKGROUND DATA ON SERVICE USERS

This information is gathered through reading of case files prior to the interviews and some points are clarified during the interviews.

- 1.1 Name
- 1.2 Year of Birth
- 1.3 Gender
- 1.4 Year of admission in Home or membership
- 1.5 Marriage status
- 1.6 Employment
- 1.7 Assistance provided by organisation
- 1.8 Impairment
- 1.9 Race

2. SEMI-STRUCTURED INTERVIEW QUESTIONS

- 2.1 Discussion on WORK experience - is he/she happy with it, problems associated with work -unfriendly environment as well as access related issues in the workplace, income levels and future scope, What choices and options do they have and their perception of success.

- 2.2 Discussion on the ORGANISATION (CC or SH)) - reflections on assistance provided - who made assessment of needs and level of user participation in this process.

User involvement in the organisation - what part the individual plays and likes to play, opportunities for feedback, group support & discussion on problems, staff & committee members roles, levels of communication etc.

- 2.3 Discussion on FAMILY & FRIENDS- nature of relationship and support received. Has the family been a hindrance or support to self reliance/ independence and their attitude towards disability.

- 2.4 Discussion on MOBILITY and BARRIER FREE ACCESS: Problems encountered in using the current unfriendly public transport system TRANSPORTATION, and HOUSING facilities available.

- 2.5 Discussion or comments on CULTURAL & RELIGIOUS EXPERIENCE - images and perceptions of disability.

- 2.6 Discussion on PERSONAL DEVELOPMENT MATTERS - whether they were denied opportunities in education/vocational training in early childhood as a result of their disability and its impact upon them now (self-confidence). What opportunities are there now for them to alter this denial?

3. STRUCTURED INTERVIEW QUESTIONS

3.1 Please clarify your NEEDS in order of priority most urgent (1) to least urgent (5).

NEEDS	ORDER OF URGENCY				
Personal assistance & Personal care	1	2	3	4	5
Health & Medical needs	1	2	3	4	5
Financial & Employment needs	1	2	3	4	5
Friendship & Recreation	1	2	3	4	5
Marriage & Family needs	1	2	3	4	5
Transportation	1	2	3	4	5
Housing	1	2	3	4	5

3.2. Who provides the support needed ?

	Personal	Family	Organisation	Other Org.	Govt.
PA & PC					
H & MN					
F& EN					
F&R					
M&F					
T					
H					

3.3 Are you satisfied with the assistance ? Indicate from a scale of most satisfied (1) to least satisfied (5).

Personally provided	1	2	3	4	5
Family & relatives	1	2	3	4	5
Organisation (Cheshire/POCAM)	1	2	3	4	5
Another organisation	1	2	3	4	5
Government	1	2	3	4	5

Appendix 5

SOCIAL WORK PRACTICE QUESTIONNAIRE

1. Personal Particulars

Name :

Organisation

Position in organisation

Age

Gender: Male / Female

Indicate if you are a disabled person or parent of disabled person Yes No

- if yes please indicate impairment

2. Rank in order of importance the following reasons which hinder active involvement of disabled people in meeting their own needs. Most important (1) to least important (5)

Negative attitudes by non-disabled persons towards the potential of disabled people	1	2	3	4	5
Negative cultural and religious views that portray disability as a curse	1	2	3	4	5
Over caring and proactive role of parents	1	2	3	4	5
Over caring and protective role of voluntary organisations and caring staff	1	2	3	4	5
Inferiority feelings by disabled people	1	2	3	4	5
Lack of initiative by disabled people to organise themselves	1	2	3	4	5
Unwillingness by non-disabled people in voluntary agencies to share power	1	2	3	4	5
Lack of encouragement by voluntary agencies for disabled people's involvement in decision making	1	2	3	4	5
No policy or legislation requiring voluntary agencies to incorporate disabled people	1	2	3	4	5
Prevailing view and perception of society in caring for disabled people	1	2	3	4	5

3. Which in your opinion is the dominant view in social work practice today in Malaysia. Tick only one.
- ☐ Helping disabled people cope with their disability at the personal, individual and family level
- ☐ Helping disabled people change the disabling environment
- ☐ Both of the above
4. Which in your opinion should be the dominant view for social work practice in the future in Malaysia. Tick only one.
- ☐ Helping disabled people cope with their disability at a personal, individual and family level.
- ☐ Helping disabled people change the disabling environment
- ☐ Both of the above
5. Which in your opinion should be the approach to social work practice. Tick only one.
- ☐ Charity and custodial care
- ☐ Equal opportunities and empowerment
- ☐ Both of the above
6. Should disabled people be given an opportunity in organisations 'for' disabled people to play an active part, hold office and be involved in decision making.
- ☐ Yes ☐ No
7. Should persons with learning difficulties be encouraged to develop leadership skills and active involvement in voluntary organisations.
- ☐ Yes ☐ No
8. Should there be legislation or clear policy to ensure voluntary organisations include disabled people in electoral office and decision making.
- ☐ Yes ☐ No

9. Rank in order of priority the most urgent (1) to the least urgent (5).

Registration of disabled people	1	2	3	4	5
Drafting a Disability Legislation on Equal Opportunities	1	2	3	4	5
Organising disabled people into self help/ self advocacy groups	1	2	3	4	5
Educating & Training disabled people	1	2	3	4	5
Lobbying government for greater financial allocations and appropriate policies	1	2	3	4	5
Open employment & sheltered workshops	1	2	3	4	5
Public awareness on rights and potential of disabled people	1	2	3	4	5
Co ordination of services provided by voluntary organisations	1	2	3	4	5
Research & Resource development	1	2	3	4	5
Upgrading staff knowledge & skills	1	2	3	4	5

10. Any other comments

Appendix 6

INTERVIEWEE'S PROFILE - Organisational interviews

(Using appendix 3)

All names pseudonyms

Name	Age	Gender	Impairment / Parent	Organisation of / for	Role in organisation
Hasan	31	male	disabled person (dp)	for	EO
Ling	34	female	disabled person	of	EO
Ting	22	female	dp	of	SS
Sarah	20	female	dp	of	EO
Ahmad	42	male	dp	for	ES
Ali	39	male	dp	of	EO
Florence	35	female	dp	of	EO
Rositha	36	female	non dp	for	EO
Mercy	36	female	non dp	for	SS
Soon	35	female	non dp	for	SS
Ping	32	female	non dp	for	SS
Mariam	45	female	non dp	for	SS
Rosli	52	male	non dp	Dept. Social Welfare (DSW)	ES
Hasmah	46	female	non dp	for	EO
Ping Lee	45	female	non dp	for	ES
Cheng Siew	35	female	dp	of	ES
Raman	37	male	dp	DSW	ES
Chong	77	male	non dp	for	EO
Yong	40	male	parent	for	EO

* Elected Official (EO), Executive Staff (ES), Service Staff (SS)

Appendix 7

INTERVIEWEE'S PROFILE -CHARITY SERVICE USERS

(Using appendix 4)

- All names pseudonyms

Name	Age Years*	Race	Gender	Impair- ment **	Family	Employ- ment* **
Siva	38 29	Indian	Male	Spastic, speech diff	Single	SW
Foo	37 27	Chinese	Male	Polio	Single	SE
Florist	47 18	Chinese	Female	Polio	Married to resident	SW
Meena	25 15	Indian	Female	Polio	Single	OE
Guan	40 12	Chinese	Male	Quardra- plegic	Single	OE
Fatimah	31 4	Chinese Muslim	Female	CP	Single	OE
Ahmad	24 3	Malay	Male	CP	Single	OE
John	32 1	Mix.	Male	Paraplegic	Single	OE
Glory	40 27	Chinese	Female	Spastic	Single	SW
Gopal	46 7	Indian	Male	Paraplegic	Separated	UE
Chee	28 19	Chinese	Female	Spastic	Single	SW
Kiong	45 28	Chinese	Female	Spastic	Single	SW
Muthu	42 28	Indian	Male	Osteogen- esis	Single	SW
Lisa	35 3	Malay	Female	Cerebellar Atrophy	Single	SW

* Number of years living in residential care

** As defined by the organisation, derived in the case files.

*** Sheltered Workshop (SW), Open Employment (OE), Self Employed (SE),
Unemployed (UE)

Appendix 8

INTERVIEWEE'S PROFILE - SELF HELP SERVICE USERS

(Using appendix 4)

- All names pseudonyms

Name	Age Years*	Race	Gender	Impair- ment**	Family	Employ- ment ***
Kassim	26 2	Malay	Male	Spinal paraplegia moto acc.	single	SE
Wong	44 13	Chinese	Male	Polio fr. childhood	married nd 3 children	OE
Vellu	22 2	Indian	Male	spinal paraplegia moto acc.	single	SE
Singam	36 3	Indian	Male	spinal par moto acc.	married ndp	SE
Leong	44 20	Chinese	Female	polio	widow	SE
Lim	43 19	Chinese	Male	wheel chair	married dp	SE
Osman	25 3	Malay	Male	one weak leg	single	OE
Ismail	40 18	Malay	Male	one weak hand	Married 5 children	OE
Ratnam	34 5	Indian	Male	polio	single	OE
Krishnan	52 13	Indian	Male	walking stick -acc.	married- 2 child	OE
Musa	52 2	Malay	Male	spinal par via acc.	Married with child.	UE
Razak	57 13	Malay	Male	Spastic	divorced six chi.	UE
Yusof	36 20	Chinese Muslim	Male	Polio both legs	single	SE
Cheng	37 18	Chinese	Female	Polio	single	OE

* Number of years as member of the SHO

** As defined by the organisation, derived from the case files.

*** Self-Employed (SE), Open employment (OE), Unemployed (UE).

Appendix 9

INTERVIEWEE'S PROFILE - FEEDBACK ON CITIZENSHIP MODEL

(Using appendix 5)

-All names pseudonyms

Name	Age	Gender	Impairment/ Parent	Organisation of / for	Role in organisation
Shanti	40	Female	disabled person	of	EO
Misbun	30	Male	disabled person	for	EO
Kamal	47	Male	disabled person	University	A
Ding	53	Female	disabled person	of	EO
Julius	38	Male	disabled person	of	EO
Michael	48	Male	disabled person	for	ES
Paul	65	Male	disabled person	of	EO
Timothy	47	Male	disabled person	of	EO
Faridah	45	Female	Parent	for	EO
Foo	49	Male	Parent	of	EO
Loo	32	Male	non disabled	for	ES
Pat	38	Female	non disabled	for	EO
Clement	67	Male	non disabled	for	EO
Selvom	44	Male	non disabled	University	A

*Elected official (EO), Executive staff (ES), Academic (A)